Medical frontiers: debating mitochondria replacement

Annex IV: Summary of the 2012 open consultation questionnaire

Report to: Human Fertilisation and Embryology Authority

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Executive summary

About the consultation

The Office for Public Management (OPM), in partnership with Forster and Dialogue by Design (DbyD), was commissioned by the Human Fertilisation and Embryology Authority (HFEA) to conduct a multi-method research and engagement project looking at the possible social and ethical issues relating to two techniques for the avoidance of mitochondrial disease: pronuclear transfer (PNT)[1] and maternal spindle transfer (MST)[2].

As part of this research and engagement, *Medical Frontiers: debating mitochondria replacement*, an **open consultation** ran from 17 September to 7 December 2012.

Respondents were invited to consider a range of information presented on the consultation website, and to respond to seven questions using the online questionnaire.

A total of **1,836 responses** were received, the majority of which were via the consultation website. Respondents include stakeholder organisations, individuals with personal experience of mitochondrial disease, as well as many members of the public.

The consultation process was managed by Dialogue by Design (DbyD), a company specialising in managing large or complex consultation processes. DbyD received, processed and analysed all responses to the consultation in close liaison with the HFEA.

It is important to note that the open consultation provided an opportunity to participate for individuals and organisations keen to have their views heard. As anyone who wanted to could participate, the views expressed **cannot be considered representative of the wider population**.

Emerging themes

The consultation questionnaire asks respondents to consider a number of questions relating to making MST and pronuclear transfer PNT techniques available to people at risk of passing on mitochondrial disease to their child.

Throughout responses to all consultation questions a number of themes are highlighted repeatedly, mostly as part of a narrative that is either supportive of the introduction of the techniques, or one that articulates opposition.

Respondents who argue against the introduction of mitochondria replacement techniques often express concern that such a move would cross an ethical boundary or amount to inappropriate interference with the natural or spiritual aspect of reproduction. Many specify that they believe it is problematic that children born as a result of the techniques will carry DNA from three people, for a range of reasons further discussed below. Another strand to some respondents' opposition is the creation and destruction of embryos as part of PNT, which in their view is unethical.

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[1] Pronuclear transfer involves transferring the pronuclei from an embryo with unhealthy mitochondria and placing them into a donor embryo which contains healthy mitochondria and has had its pronuclei removed. A pronucleus is a small round structure containing nuclear DNA seen within an embryo following fertilisation. A normal embryo should contain two pronuclei, one from the egg (maternal pronucleus) and one from the sperm (paternal pronucleus).

[2] The maternal spindle is a structure within the egg containing the mother's nuclear DNA. Maternal spindle transfer involves transferring the spindle from the intended mother's egg, with unhealthy mitochondria, and placing it into a donor egg with healthy mitochondria.

Respondents who argue in favour of the introduction of mitochondria replacement techniques often emphasise the benefits of the techniques to families affected by mitochondrial disease. Many say they believe it is important - some say there is an ethical imperative - to avoid or eradicate the disease, sometimes referring to the suffering that patients may endure. Respondents who support the techniques also tend to employ arguments about the genetic significance of donated mitochondria (or mitochondrial DNA), which they believe is limited and therefore not a great concern. This is further explored in the sections below.

An additional theme emerging both in responses arguing against the techniques and in responses arguing in favour is the **management of risk**. For many respondents supporting mitochondria replacement in principle it is crucial that sufficient evidence is available about the safety of the techniques before they are allowed in a clinical setting. Other respondents highlight that risks cannot be fully managed and that this is part of the reason why they oppose the introduction of mitochondria replacement techniques.

Consultation questions

Responses to each of the seven consultation questions are discussed below, focusing on issues specific to those questions.

Question 1

Asked for their **views on offering MST and PNT** to people at risk of passing on mitochondrial disease to their child, just over 500 respondents say they do not think the techniques should be permitted, while almost 500 say that they support the introduction of both techniques. Most respondents with direct or indirect experience of mitochondrial disease argue in favour of the introduction of the techniques.

Where respondents support one technique in particular, they tend to prefer MST because this technique replaces mitochondria in eggs rather than embryos.

Question 2

Respondents are asked in question 2 whether they think there are social and ethical implications to **changing the germline**.

Those in favour of the techniques argue that there are **no negative implications** or that these are outweighed by the positives. Respondents who oppose the introduction of the techniques specify a range of potential implications, highlighted below.

With regard to the germline the most prominent concern expressed is that consequences of the techniques will affect many **generations down the line**, and that these consequences are to some extent unknown.

Another potential implication outlined in some respondents' views is that making changes to the germline for this purpose could **lead to other changes** becoming more acceptable: many respondents identify the idea of germline change with cloning or the creation of designer babies.

Others argue that any change to the germline is inappropriate because there is no way for all those affected to give **consent**; a view contradicted by a few who see making choices for subsequent generations as a very ordinary part of being a parent.

Question 3

When asked in question 3 whether they think the techniques have social or ethical implications relating to **a person's sense of identity**, respondents' comments differ widely.

Respondents who believe such implications will be **minor or non-existent** often argue that identity is more a social than a genetic concept, that mitochondrial DNA has no function in determining an individual's characteristics, and that other procedures currently used (including adoption and gamete donation) are likely to have similar or greater implications.

Respondents who consider that implications are likely often say that knowing they carry DNA from three people may saddle children with questions about who they are, and who their parents are, which they say will have a detrimental impact on their **well-being**. Some respondents argue that adopted or donor-conceived children suffer from identity issues and that children resulting from mitochondria replacement could experience similar problems, or worse. A number of respondents think that children born as a result of using PNT might also feel unhappy about the creation and destruction of embryos as part of their conception.

Many respondents believe that parents will be able to **mitigate** any identity implications by being open about how the child is conceived.

Question 4a

The consultation questionnaire asks how respondents **view the status of a mitochondria donor** compared to other, existing types of donor. Views differ diametrically on this topic, with mitochondria donation seen as similar to, and different from, each existing type of donation by roughly equal numbers of respondents.

The most frequently made comparisons are with **gamete donation**, closely followed by **tissue, organ and bone marrow donation**. Generally speaking it is the genetic significance of mitochondria donation that informs respondents' comparisons, with those believing mitochondrial DNA is of greater significance more inclined to compare with gamete donation, and others more inclined to compare with organ, tissue or bone marrow donation.

Question 4b

This question asks respondents about their views on possible models for governing the disclosure of **information about the mitochondria donor** to the child.

The consultation questionnaire outlines three possible models, each of which are supported by more than 100 respondents. Most of these believe **children should not know the identity** of their mitochondria donor, with opinion divided on whether medical and personal information should be available. About 150 respondents think **children should be able to contact their mitochondria donor** once they reach the age of 18. Some respondents offer alternatives to the models proposed in the question, including suggestions for more flexible arrangements.

Respondents often indicate that their preference is informed by whether or not they regard the mitochondria donor as **a third parent** of the child, with those who think of the donor as a parent more inclined to favour a model that allows contact.

Several respondents think that donors should **consent** to the information that is disclosed, in particular for the model where the donor's identity would be made available to the child. Others argue that the disclosure of identity is part of the responsibilities of the donor.

Respondents who oppose the introduction of the techniques generally do not discuss the models and reaffirm their **opposition** instead.

Question 5

In question 5 respondents are asked to indicate a preference for one of three possible **models of regulation** if the law were to be changed to allow mitochondria replacement to be carried out in specialist clinics.

Almost half of the respondents to this question decline to express such a preference, and instead note their objection to mitochondria replacement.

Of those respondents who indicate a preference for a particular model of decision making, close to half opt for a system in which **clinics and individual patients** would make a case-by-case decision about whether or not to use mitochondria replacement (option 1). This preference is often associated with a view that a central regulatory board may lack sensitivity to individual circumstances and a feeling that individual patients should be empowered to choose the best option for their own families.

A similar number of respondents prefer an option that includes a **role for the regulator** (option 2 and option 3). Many feel that an external regulatory framework would provide a buffer against abusive profiteering and promote fairness by making sure that the same criteria are applied for all applications for treatment.

Most respondents who think there is a role for the regulator express a preference for a **broad regulatory framework** in which the regulator sets overall criteria within which patients and clinicians can decide on a case-by-case basis. A minority of respondents express a preference for a model in which a central regulator would maintain responsibility for making decisions about particular cases.

Question 6

In question 6 of the consultation questionnaire, respondents are **asked whether they believe the law should be changed** to allow mitochondria replacement techniques to be made available to people who are at risk of passing on mitochondrial disease to their child.

A majority of these respondents argue against changing the law, while a substantial minority argue in favour.

Those **arguing against a law change** sometimes refer to the international context and see it as problematic that the UK would be the first or only country to allow the use of MST and PNT. Several respondents argue that other methods should be considered before forging ahead with these new techniques.

Respondents **arguing in favour of law change**, and particularly those adding caveats to their support, highlight a variety of criteria they think need to be met. Respondents also suggest that further work is undertaken to specify which of the techniques (MST and/or PNT) should be allowed, and in which circumstances.

Question 7

The final consultation question asks respondents whether there are any **other considerations** they think decision makers should take into account.

In addition to reiterating points they made in response to earlier questions, some respondents highlight that decision makers should particularly consider the **views of certain groups** such as patients and relatives, scientists, and religious groups. With regard to the latter there are responses urging decision makers to not give undue consideration to these.

Chapter 1 Introduction

Mitochondria are present in almost all human cells. They are often referred to as the cell's 'batteries' as they generate the majority of a cell's energy supply. For any cell to work properly, the mitochondria need to be healthy. Unhealthy mitochondria can cause genetic disorders known as mitochondrial disease.

There are many different conditions that are linked to mitochondrial disease. They can range from mild to severe or life threatening, and can have devastating effects on the families that carry them. Currently there is no known cure and treatment options are limited. For many patients with mitochondrial disease preventing the transmission of the disease to their children is a key concern.

Mitochondrial disease can be caused by faults in the genes within a cell's nucleus that are required for mitochondrial function or by faults within the small amount of DNA that exists within the mitochondria themselves. It is the latter form of mitochondrial disease that could be avoided using two new medical techniques, termed pro-nuclear transfer (PNT) and maternal spindle transfer (MST) which UK researchers are working on.

These techniques are at the cutting edge, both of science and ethics and are currently only permitted in research. They involve removing the nuclear DNA from an egg or embryo with unhealthy mitochondria, and transferring it into an enucleated donor egg or embryo with healthy mitochondria.

The Human Fertilisation and Embryology Act (1990) (as amended) ('the Act') governs research and treatment involving human embryos and related clinical practices in the UK. The Act currently prevents the clinical use of these techniques (or any other technique that involves genetic modification of gametes and embryos to treat patients). However, in 2008 the Act was amended, introducing new powers which enable the Secretary of State for Health to permit techniques which prevent the transmission of serious mitochondrial disease. The Secretary of State for Health and the Secretary of State for Business, Innovation and Skills asked the Human Fertilisation and Embryology Authority (HFEA) to seek public views on these emerging techniques. On considering advice from the HFEA the Government will decide whether to propose regulations legalising one or both of the procedures for treatment.

The HFEA, together with the Sciencewise Expert Resource Centre3, therefore commissioned OPM (in partnership with Forster and Dialogue by Design) to conduct a multi-method research and engagement project looking at the possible social and ethical issues and arguments relating to the techniques. The project consisted of five strands:

1. Deliberative public workshops
2. Public representative survey
3. Patient focus group
4. Open consultation meetings
5. Open consultation questionnaire

As part of this range of activities to seek views of members of the public, the HFEA conducted a open consultation on mitochondria replacement in the autumn of 2012. This report provides a

[3] The Sciencewise Expert Resource Centre (Sciencewise-ERC) is the UK's national centre for public dialogue in policy making involving science and technology issues.

summary of the responses to the consultation, which was run by an independent specialist company.

The findings of the consultation have also informed the Summary of Evidence which is published separately, and also contains findings from other dialogue and research activities. The overview report also contains an introduction to the techniques and the issues the HFEA is considering as part of their duty to provide recommendations to Government.

Chapter 2 The consultation process

2.1 Summary of consultation activities

The HFEA's public consultation on *Medical Frontiers: debating mitochondria replacement* ran from 17 September to 7 December 2012. It followed an intensive and wide-ranging programme of dialogue and research carried out in the spring and summer of 2012, and the findings from these stages informed the consultation questionnaire. This report covers the public consultation only; please see the Summary of Evidence for summaries of other engagement activities. The purpose of the public consultation was to gather public views on the social and ethical impact of making the proposed techniques available to patients. The HFEA will consider these views when they prepare their recommendations to Government.

The consultation was open to all. Respondents were invited to consider a range of information presented on the consultation website, and to respond to seven questions using the online questionnaire. Although the consultation website encouraged respondents to consider the information presented, respondents may have preferred to respond without considering this information, or to use other sources to inform their response. Respondents were not asked to indicate which information they consulted, so this has not been used as a variable in the analysis or the report.

The consultation documents recommended the use of the online questionnaire, but responses made via email or post were also accepted while the consultation was open. The consultation was managed by Dialogue by Design (DbyD), a company specialised in managing large or complex consultation processes.

The public consultation was an open process, which means that respondents cannot be considered a representative sample of the UK population, as one would expect to find in a survey or referendum. Rather, the consultation attracted responses from individuals and organisations who chose to respond. Its main purpose is to help the HFEA understand the range of views held by respondents as well as the arguments underpinning these views. Although it can be helpful to consider how many respondents express certain views, this is not the primary aim of the consultation or indeed this report.

The HFEA also held two public meetings in London and Manchester, which gave members of the public a chance to share their views in person. The events included a panel of experts who gave some information about the techniques and took questions from the attendees, as well as a chance for members of the public to discuss the issues. These meetings have been reported on separately and have also been covered in the Summary of Evidence.

2.2 Responses

A total of 1,836 responses to the consultation were received. Most of these were submitted via the consultation website. Additionally, 524 letters and emails were received. A further 45 respondents completed a response form.

Table 1 Overview of response types

Response type	Count
Online questionnaire	1,260
Paper-based response form	45
Letters and emails	524
Total	1,836

Not all respondents answered all consultation questions. In fact, some respondents answered none of the questions, but sent a generic letter or email in which they set out their views. Table 2 below provides an overview of the number of responses each consultation question received.

Table 2 Overview of responses per consultation question

Question	Count of responses
Question 1	1,235
Question 2	1,114
Question 3	1,084
Question 4a	987
Question 4b	1,039
Question 5	1,143
Question 6	1,055
Question 7	883
Other responses, not specific to consultation questions	503

2.3 About the respondents

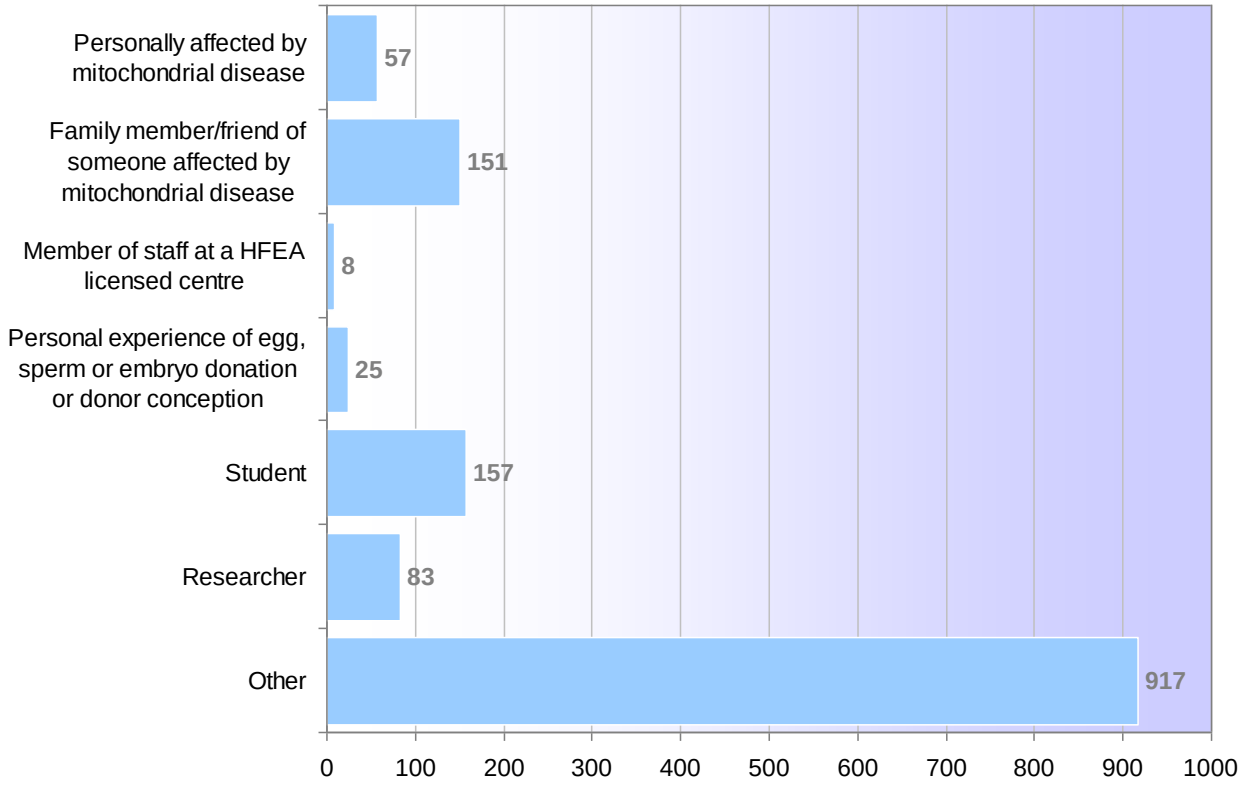
Respondents who used either the consultation website or a response form were asked to answer a small number of questions about themselves, specifying their background and the nature of their interest in the consultation. The responses to these questions are summarised here.

A total of 66 respondents specified that their response was submitted on behalf of an organisation. A list of organisations who participated in the consultation is provided in appendix 2.

The questionnaire also asked respondents to select from a series of listed options which best described them. Respondents could select more than one option if appropriate. An overview of the responses to this question is given in figure 1 below. This respondent information could not be collected for those who responded by email or letter.

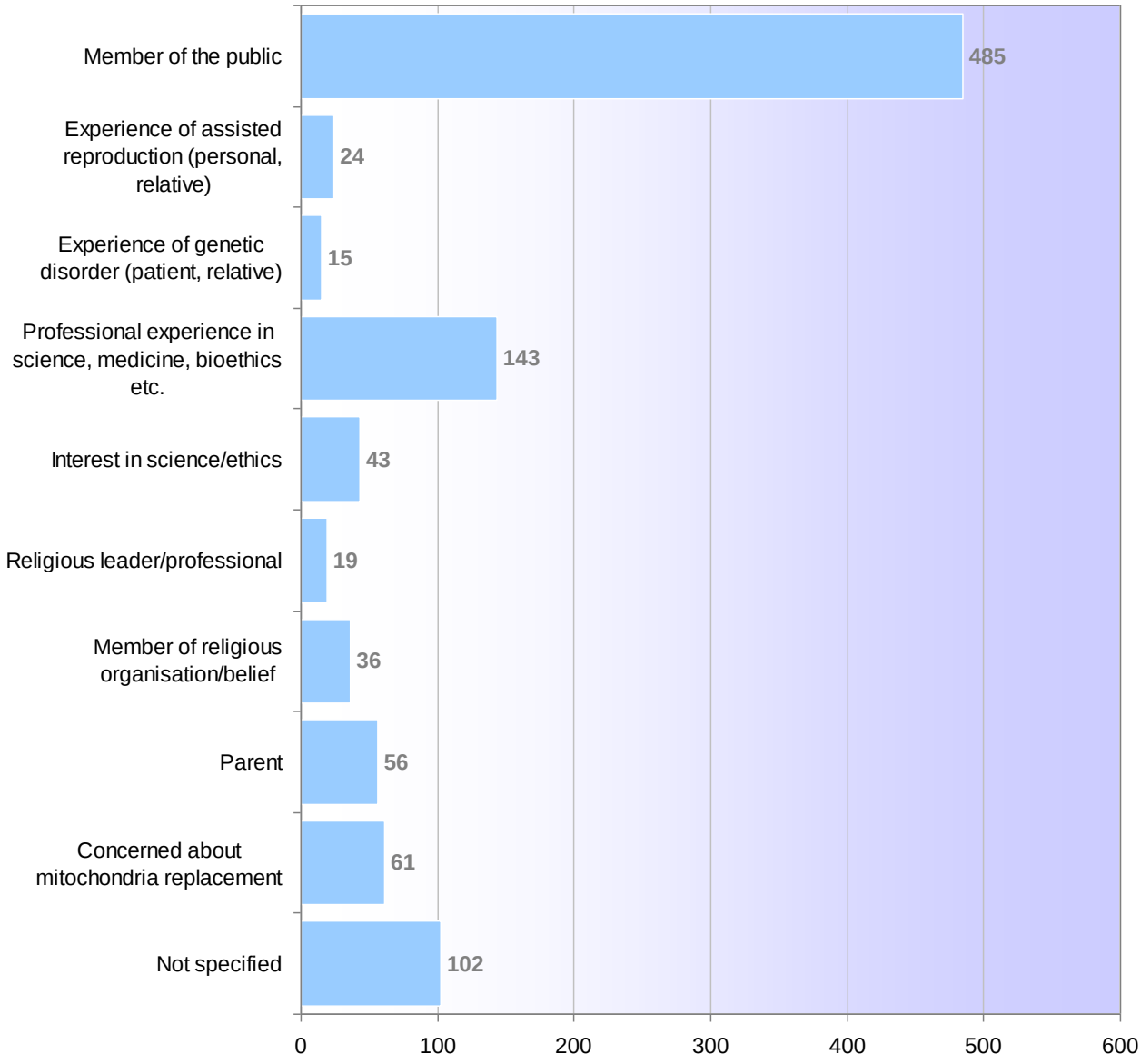
Figure 1 shows that most respondents did not describe themselves as belonging to one of the categories specified in the questionnaire, with 917 respondents choosing 'Other'. Of those who did identify with listed options, 157 respondents indicated they were students and 83 that they were researchers. A total of 151 respondents specified that they were a family member or friend of someone affected by mitochondrial disease; 57 respondents indicated that they themselves were affected. Also, 25 respondents indicated that they had personal experience of egg, sperm, embryo donation or donor conception and 8 respondents identified themselves as staff members at a HFEA licensed centre.

Figure 1 Respondent types (online only)



As is shown above, the majority of respondents who completed the 'About you' question ticked 'Other' and many of these specified further their interest in the consultation. Roughly half of the respondents who selected 'Other' identified themselves as 'members of the public' or 'citizens'. Smaller numbers of respondents included details about their scientific or professional background, their religious beliefs or involvement, or their experience of related diseases or procedure. A rough breakdown of the respondents within the 'other' category is shown in figure 2. Please note that many respondents included a fair bit of information, therefore sometimes respondents have been counted in multiple categories.

Figure 2 Respondent type 'other': further breakdown based on self-description



Individuals, organisations and organised responses

It is worth noting that respondents include individuals responding on behalf of themselves (or a small group of people), organisations responding on behalf of their staff or membership, as well as individuals responding in their capacity of supporters of an organisation or group. This is common for open consultation processes: there is no selection of respondents other than the choice of individuals and organisations to respond.

As discussed in section 2.1 above and further clarified in chapter 3, this needs to be kept in mind when considering the summary of responses. In particular, it is possible (and common for this type of high-profile consultation) that a proportion of the responses are a result of initiatives from groups or organisations to raise the prominence of specific points of view. This may have influenced the numbers of responses expressing either strong support for or strong opposition to mitochondria replacement.

Chapter 3 Methodology

3.1 Receiving responses

Responses were received in a number of formats: online response forms (via the website), letters and emails. All responses were received by DbyD, at which point they were assigned a unique reference number and entered into the DbyD analysis system.

Online response forms

Online responses were imported directly into the DbyD analysis system. Whilst the consultation was open, users were able to update or amend their submission. If respondents updated their submission this was imported into the analysis database with a clear reference that it had been modified, to ensure that any new information was taken into account during the analysis.

Paper response forms

Response forms received by post were logged and scanned, then manually written or copied into the analysis database by data entry staff. The data entry process followed the questionnaire structure so that these responses could be analysed in the same way as online responses. Data entry was monitored by the DbyD transcription team to ensure that responses were accurately captured.

Emails

Respondents were able to send responses directly to DbyD by email. These responses were logged, imported into our analysis system and analysed alongside the online responses.

Letters

Letters sent to DbyD were logged, scanned and written into the database by data entry staff. The data entry process was monitored by the DbyD transcription team to ensure that responses were accurately captured. Once data entry was complete responses were imported to the analysis system and analysed alongside the online responses.

Responses sent to the HFEA

A small number of responses were sent directly to the HFEA, either by post or by email. The HFEA informed respondents that their response would be considered as part of the consultation and securely transferred the responses to DbyD, where they were entered into the analysis system as described above.

Late submissions

The consultation ended at midnight on Friday 7th December. To make allowances for potential delays in the email and postal systems offline responses which arrived no later than Tuesday 11 December 2012 were included in the analysis and this report.

3.2 Analysing responses

Developing an analysis framework

In order to analyse the responses, and the variety of views expressed, an analytical framework was created. The purpose of the framework was to enable analysts to organise responses by key themes and issues so that key messages as well as specific points of detail could be captured and reported.

A three-tier approach was taken to coding, starting with high level themes, splitting into sub-themes and then specific codes. As an example, a response to question 1 containing a concern about changes to the germ line would be coded into (theme) *Arguments against* - (sub-theme) *Altering DNA* - (code) *impact on germ line/lineage*. Some themes were used more often for particular questions, while others were used equally across the questions as respondents raised similar issues. Table 3 provides a full list of the top level themes used and Table 4 provides an extract from the coding framework showing the use of themes, sub-themes and codes. The full list of themes and codes are available in appendices 3 and 4.

Each code is intended to represent a specific issue or argument raised in responses. The data analysis system allows the analysts to populate a basic coding framework at the start (top-down) whilst providing scope for further development of the framework using suggestions from the analysts engaging with the response data (bottom-up). We use natural language codes (rather than numeric sets) since this allows analysts to suggest refinements and additional issues, and aids quality control and external verification.

Table 3 Coding framework: themes

Theme	Acronym
Acceptability	AC
Arguments against	AG
Arguments in favour	FA
Considerations	CO
Consultation process	CP
Decision making	DM
Donation status	DS
Information	IN
Legal Status	LS
Other	O
References	RF
Science	SC
Social and ethical	SE

Table 4 Coding framework: example codes for SC and SE themes

Theme	Sample codes
Science	SC - DNA - natural mixing
	SC - Mitochondria - function/form
	SC - Mt DNA - does not affect identity/traits
	SC - Mt DNA - may affect identity/traits
	SC - other procedures - organ/tissue/blood donation
Social and ethical	SE - Ethical - end does not justify means
	SE - Ethical - ethical imperative to intervene
	SE - General - similar to other procedures
	SE - Social - child awareness/understanding
	SE - Social - donor/child relationship
	SE - Social - overall societal impact

Applying the analysis framework

The analysis team, supervised by the senior analysts who developed the coding framework, worked systematically through each response to the consultation, applying the relevant codes to capture the issues raised. The application of a code from the framework was done simply by highlighting the relevant text and recording the selection. A single response would receive multiple codes to capture the various issues raised by each respondent.

The coding of responses to each question was regularly checked and reviewed by senior analysts to ensure quality and consistency. In addition, HFEA was able to view analysed responses throughout the analysis stage and provide feedback on the coding when required.

3.3 About this report

This report provides a summary of the responses to the HFEA consultation on *Medical frontiers: debating mitochondria replacement*. It gives a flavour of the issues raised in response to each of the consultation questions.

As outlined above, this report is produced to help the HFEA understand the range of views held by respondents as well as the arguments underpinning these views. For that reason it is not written with a view to identify majority views, or to emphasise points made by greater numbers of responses only. Rather the report aims to present minority views alongside those held by many, so that each issue is discussed in a manner that does as much justice as possible to the wealth of suggestions presented in responses.

Summarising a variety of response types

The structure of this report mirrors the structure of the consultation questionnaire (see appendix 1), with a chapter dedicated to each consultation question. Each chapter summarises views expressed in response to the question it covers. This includes comments from stakeholder organisations as well as individuals. The report aims to provide an accurate summary of all respondents' views and efforts were made to ensure that it amply covers responses from organisations as well as individuals.

Chapter 2 includes a breakdown of respondent categories based on what respondents indicated when asked to define their interest in the consultation. Where relevant the report specifically looks at the responses from a particular category of respondents, for instance to consider the views of those with experience of gamete donation on the status of the mitochondria donor.

As specified in chapter 2, not all respondents used the consultation questionnaire: some 500 responses received as emails and letters did not refer to the consultation questions. Non-questionnaire responses were analysed in the same way as questionnaire responses, making up an additional 'question' in the database. In the report, the issues most prominently discussed in these responses are discussed in the most relevant chapter, i.e. comments about changing the law are discussed in chapter 10. As these responses are not directly addressing the consultation question, they are discussed separately from the other responses, and set apart by a different layout.

Both among questionnaire and non-questionnaire responses there are numerous respondents making similarly or identically worded arguments. This indicates that there may have been initiatives to encourage people to respond to the consultation in a certain way. While this does not make such responses less valid or valuable than others, it is important that readers of the report are aware of this. To accommodate this, the report clarifies where particular views are made by many respondents using the same words or suite of arguments.

Numbers and quantifying terms

Where the report refers to how many respondents have raised a specific issue, it is important to keep in mind that this was an open and qualitative consultation process rather than a way to establish dominant views across a representative cross-section of the public. The numbers in the report are useful in clarifying where issues are seen as important by many or by a few respondents. Beyond that, however, they cannot be seen to serve any statistical purposes. This is also true for the numbers reported on in chapters 8 and 9, where the closed questions of the questionnaire are discussed and charts are included to summarise responses.

Similar to the above, the report contains words like 'many', 'some', 'a few' in order to indicate the distribution of opinions among respondents on particular topics. In this way these terms help clarify whether viewpoints discussed are raised by greater or smaller numbers of respondents. The words are only very rarely used in relation to the total number of respondents to the consultation. Rather, the use of these words depends on their context, i.e. 'many' should not be regarded as indicating a precise numeric range.

Info-graphics

The following chapters of the report each contain an info-graphic presenting a diagram of the topics emerging in responses to the consultation question discussed in that chapter. These diagrams aim to clarify how the report breaks down the wide range of issues relating to each consultation question; they do not indicate any further or deeper interpretation of the data.

Quotes

Throughout the following chapters quotes from respondents have been used to illustrate the points raised. Where responses from organisations are quoted, the name of the organisation is mentioned; individual respondents are not identified by name when quoted.

Use of the terms social and ethical

Several consultation questions ask respondents to consider whether the techniques have social or ethical implications. As part of the analysis of these and other questions a distinction was made between implications, or issues, that could be described as ethical and others that would primarily

be social. The distinction used throughout the analysis brands arguments relating to ideologies and value systems as *ethical* and arguments relating to impact on individuals or groups in society as *social*. This distinction has been used consistently across the consultation questions. In this regard it is important to remember that the report merely aims to summarise responses; further interpretation is outside the scope of this report.

Chapter 4 Question 1: permissibility of new techniques

4.1 Headline findings

The first question asks:

> **Q1: Having read the information on this website about the two mitochondria replacement techniques – maternal spindle transfer and pro-nuclear transfer, what are your views on offering (one or both of) these techniques to people at risk of passing on mitochondrial disease to their child? You may wish to address the two techniques separately.**

1,235 responses were made to this question.

Most respondents took this opportunity to express their view about the acceptability the techniques - with approximately equal numbers supporting and opposing their introduction into clinical practice. Most respondents commented on the acceptability of the techniques taken together or without distinguishing between them: 349 state that they consider both acceptable, while 106 agree but with some caveats, but 502 say they are not acceptable. Among those commenting on the MST technique alone, 20 say the technique is acceptable, compared to 3 who agree with caveats and 2 respondents who say it is not acceptable. Conversely, no respondents commenting on the PNT technique alone say that it is acceptable, but 3 say it is acceptable while acknowledging some caveats, and 24 state that it is not acceptable.

Proponents of the techniques tend to focus on social outcomes, particularly the potential to avoid disease and allow parents the opportunity to have a healthy child. Some feel that if the techniques are possible, there is an ethical obligation to implement them. In contrast those opposing the techniques are more likely to discuss ethical issues, often arguing that use of the techniques would amount to inappropriate interference with the natural or spiritual aspect of reproduction. Others focus on the use of embryos, particularly in relation to PNT, arguing that any artificial or in-vitro manipulation of embryos is unethical. Where respondents support one technique in particular, they tend to prefer MST because it involves eggs rather than embryos. A few respondents say they favour PNT, sometimes stating that this technique has a greater success rate.

Looking at respondent types, there is a visible pattern with regard to their view on the acceptability of the techniques. Among those who describe themselves as ‘other’, there are 453 respondents stating that the techniques are not acceptable and 156 respondents saying they are. For each of the other respondent categories, such as ‘student’ and ‘family member or friend affected by mitochondrial disease’, more respondents say they find the techniques acceptable than unacceptable. Of the respondents describing themselves as personally affected by mitochondrial disease 36 think the techniques are acceptable and three think they are not.

Non-questionnaire responses

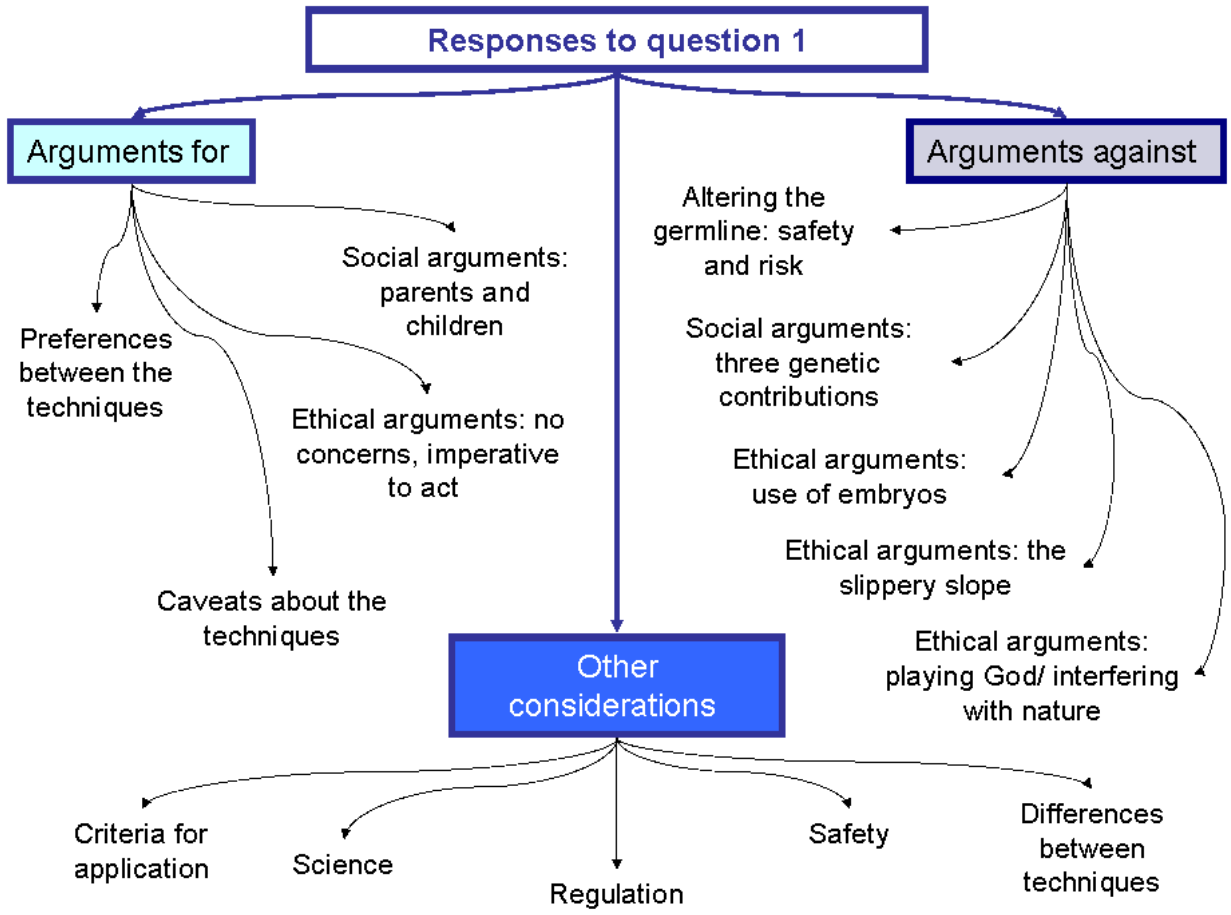
Comments on the permissibility of the techniques are also abundant in the 503 non-questionnaire responses to the consultation. These responses include a large number of letters and emails which make a similar range of arguments, often using very similar wording. Some 300 respondents state that they do not think either of the techniques are acceptable. Often this statement is accompanied by concerns about the use of embryos and/or the idea that children will carry DNA from three people. Respondents also express concern about possible unintended long-term consequences of mitochondria replacement. Some respondents believe the techniques will lead to

the acceptance of cloning and/or designer babies. A substantial number of those who argue against the techniques refer to their religion.

Some 40 respondents who sent a letter or email believe that mitochondria replacement techniques are acceptable. Many of these refer to a particular case of a child that was born with mitochondrial disease, while others sometimes point to the impact of the disease on patients and families more generally.

These arguments and others raised by respondents to question 1 are explored in more detail below under the following sub-headings:

Figure 3 Responses to question 1



4.2 Summary of comments

4.2.1 Arguments for the introduction of the techniques

60 respondents express their support for the introduction of the two techniques without adding any further explanation. Around 400 respondents give an explanation of their support, as summarised here. Stakeholder organisations expressing support include the British Medical Association, the Humanist Society Scotland, and the Association of Clinical Embryologists (ACE) Executive Committee.

Social argument: parents and children

The most common reason given by those in support of the techniques is the importance of the health of children, with many respondents seeing the techniques as an opportunity to prevent

future suffering which should not be passed up. As in the quote below, a large proportion of those responding in favour of the introduction of the techniques feel that the outcomes of these techniques are so obviously positive that there is no real reason to oppose them.

> "If by introducing both these techniques, we can wipe out mitochondrial diseases and the suffering that goes with it, then it can only be a good thing."
>
> Individual, Personally affected by mitochondrial disease; Family member/friend of someone affected by mitochondrial disease

Some respondents focus more specifically on the principle of avoiding or eradicating disease, seeing it as a categorically positive step, and supporting both research and introduction of new techniques which can prevent disease. Other respondents talk more generally about scientific progress as beneficial to society. Some respondents specifically address mitochondrial disorders, with some arguing that the potential severity of the symptoms means the benefits of the techniques outweighs any risks or costs they perceive. Personal experience of mitochondrial disease, and other hereditary disorders, is a factor for many respondents who support the techniques.

Another of the most prevalent arguments for introducing the techniques comes from respondents who talk about the benefits to current and potential parents, describing the techniques as giving them a 'chance' to have a healthy child, without passing on the disorders. In relation to the experience of potential parents some respondents talk about the emotional experience of a parent who fears passing on a disorder to their child, particularly where the severity cannot always be anticipated. One participant who describes their own family experiences with mitochondrial disease states:

> "One cannot underestimate the amount of emotional and psychological damage inflicted on parents knowing they have passed the mitochondrial disease to their children."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

Ethical arguments: no concerns, imperative to act

There are two main strands of ethical argument from those supporting the introduction of the new techniques in question one. Many respondents simply state that they see no significant ethical concerns in the use of the techniques. Some specify that they have no ethical concerns within the clinical context of mitochondrial disorders, and a few explicitly disagree that this could lead to other uses. Others feel that because the techniques involve mitochondrial rather than nuclear DNA there is no reason to be concerned about the involvement of a third person's genetic material.

The second major ethical argument for the techniques comes from respondents who feel there is a moral or ethical imperative to intervene wherever suffering can be prevented. Respondents including the British Medical Association and the Humanist Society Scotland talk about a positive duty to help those who are disadvantaged, others feel it is morally unacceptable to restrict the availability of potentially beneficial techniques. These respondents feel that the techniques under consultation will reduce the incidence of mitochondrial disease, and that it is unethical not to take the opportunity to achieve this. For others the imperative is to give parents the opportunity to have a healthy child, or the right to choose to do so:

> "The chance to have a healthy baby is something that should be available to all couples regardless of their medical history and this is a step towards that."
>
> Individual, Student

Caveats about the techniques

There are 105 respondents including the Church of England (Mission and Public Affairs Council), the Nuffield Council on Bioethics, the Academy of Medical Sciences and the British Fertility Society who qualify their support for the techniques proposed, suggesting that there are further criteria that must be met before they would consider them acceptable. By far the most common group of criteria is to do with the safety and efficacy of the techniques. Some respondents make general statements, for example that the techniques should be made available as soon as they are 'safe', while others call more specifically for further trials or evidence to verify their safety. As noted above, many respondents who do not offer a preference between the two techniques suggest that further research to determine which is the most effective, should determine which technique is used.

> "Maternal spindle transfer (MST) and pro-nuclear transfer (PNT) have the potential to prevent mitochondrial disease in future generations, giving affected parents the opportunity to have children without the fear of passing on the condition, or of passing on the risk of having affected children to their own children.
>
> "Both of these techniques are at a research stage and there is not sufficient data available to determine which is better on the grounds of safety, efficacy and feasibility. We do not believe they should be differentiated between at this point. Research into both of these techniques should continue to assess whether they are viable as potential clinical treatments.
>
> We recognise that the two techniques used are different and could raise varying ethical concerns for different people. However the Nuffield Council concluded it was ethical for both to be explored further. Subject to further information about effectiveness and safety, when balancing the benefits of each technique, some people may wish to consider the different methods used by each technique as a factor in this decision…
>
> …We support the Nuffield Council of Bioethics conclusion that "if the PNT and MST techniques are proven to be acceptably safe and effective, on balance it would be ethical for families wishing to use them to do so. This should, however, be subject to the offer of an appropriate level of information and support."
>
> Organisation, AMRC and Genetic Alliance

Preferences between the techniques

A number of responses to this question either support maternal spindle transfer only (20), or express a preference for maternal spindle transfer over pronuclear transfer (72). The majority of these respondents discuss the fact that the MST technique involves the use of unfertilised gametes, in comparison to the use of embryos in PNT, therefore preferring MST for a range of reasons. Respondents give a range of views on this issue, with some focusing on their own personal beliefs, and others talking more about social perceptions. Some respondents express their belief that life starts at conception, and feel that PNT is unacceptable as it conflicts with that belief. Others describe feeling more 'comfortable' with MST because it involves unfertilised eggs, with some adding the caveat that if PNT is more effective this should be authorised over MST. A few respondents discuss the views of others - suggesting that because some people may feel that the use of embryos is ethically unacceptable, MST is to be preferred.

A related argument expressed by a few respondents is that both techniques should be made available, to ensure that those who feel that the use of embryos is unacceptable are still able to benefit from the research.

> "I believe it is important that this option is available, in order to ensure that as many people as possible can benefit from these techniques without regard to their views on whether life starts at conception."
>
> Individual, Other

Of respondents who do not express a preference for one technique or the other, a few specifically state that they say no real difference between the two, but more common is for respondents to say that they prefer whichever technique is proved safer or more effective.

4.2.2 Arguments against the introduction of the techniques

31 respondents express their opposition to the introduction of the two techniques without adding any further explanation. Stakeholder organisations who argue against mitochondria replacement techniques include the Church of Scotland, ProLife Alliance, and Human Genetics Alert.

Ethical arguments: use of embryos

The most commonly cited argument against the introduction of the two proposed techniques is that the creation and destruction of human embryos is unethical (231). A handful of these respondents identify themselves as either personally affected by mitochondrial disease or having a family member or friend affected by mitochondrial disease; 200 of the respondents proposing this argument describe themselves as 'other'. While many respondents note that this argument applies specifically to the case of pronuclear transfer, there are many who do not specify which technique they are referring to and a few who suggest that both involve destruction of embryos. There are also a much smaller number of respondents who express similar concerns about the ethical acceptability of the destruction of eggs, as in maternal spindle transfer.

Respondents give detailed accounts of why they feel the use of embryos in PNT is inappropriate, with a range of views. Some respondents state clearly their belief that life starts at conception, and any process that results in the discarding of an embryo is tantamount to the death of a living human. Some of these respondents use terms such as 'the sanctity of life', with a few citing specific passages from the Bible to elaborate their view. Others focus on the fact that a donor embryo is created alongside the intended parents embryo, with the transfer process resulting in only one viable embryo. They see the act of creating an embryo for this purpose, with no expectation that it will have the opportunity to develop, as an act of instrumentalisation - treating human life as a means to an end, rather than an end in itself. Some argue against this on more direct ethical grounds - believing the techniques to be fundamentally immoral, while others express concern about how the parent or child would be affected by knowledge of the 'sacrifice' of one embryo to create another.

> "This ethical dilemma would not only have to be tackled by parents but may also have to be tackled by the resulting child who may feel troubled that their life came at the cost of another's."
>
> Individual, Other

Ethical arguments: playing God and/or interfering with nature

Another key argument made by those opposing the introduction of the techniques is that they represent an 'over-stepping' of an ethical boundary by altering a predetermined outcome (70). Some respondents describe this boundary in religious terms, referring to 'playing God', or suggest that for science to take responsibility for the creation of human life undermines their belief that creation is a process outside of the human domain.

> "…there are many in this country who believe our creator God himself has spoken to us about how we should live to please him. It is clear throughout the bible that fiddling with his created order in this way would not only be wrong and yet another expression of our rebellion against him, but would have negative consequences for us as a human race, as he is our good creator and his design MUST be for our good."
>
> Individual, Other

While many of these responses argue that the techniques are unacceptable on principle, some also discuss potential negative consequences, suggesting that as procreation is a divine act it could not be recreated by science without causing harm.

Other respondents make similar arguments about overstepping boundaries, but refer to nature or evolution, arguing that using these techniques would subvert the process of natural selection which governs all biological life. Some of these respondents are concerned about unforeseen consequences of manipulating the genome, citing our incomplete knowledge. Others suggest that the expression of genetic disorders and associated failure to reproduce acts as a limiting factor on the spread of genetic mutations which would be harmful at a species level. They suggest that by overcoming this 'natural' process the techniques proposed will ultimately have detrimental consequences.

> "It is not imperative that people have their own biological children, in fact such conditions are nature's way of preventing weaknesses being passed from generation to generation."
>
> Individual, Other

Both strands of this argument are sometimes couched in terms of the greater good, with respondents anxious to note their compassion for individual sufferers of mitochondrial disorders, while maintaining that ultimately no positive benefit would be served by the introduction of the techniques.

Ethical arguments: the slippery slope

Opposition to the techniques proposed is often accompanied with concern that if they were to be introduced, this would leave the door open for other, less acceptable measures to be taken. Some 70 respondents, including LIFE Charity, refer to 'designer babies' as shorthand to describe the use of assisted reproductive techniques to select characteristics of a child before birth. Some respondents talk about the outcome: expressing feelings of moral outrage towards this type of selection, or arguing that it devalues the child to the status of a commodity - a similar line of argument to concerns about the use of embryos as a means to a medical ends.

> "I worry that each new step, even if taken for noble concerns such as preventing disease, will only stir up a chorus of voices demanding more and more frivolous treatments be available, such as sex selection. Children are a gift, and not something that should be available to custom-order."
>
> Individual, Other

While a relatively large number of respondents who oppose the techniques express concerns about the potential for reproductive cloning to become possible as a result of the 'slippery slope' little detail is given about this particular possibility. Other respondents raise the concept of eugenics, arguing that the techniques effectively 'prevent' the birth of individuals with particular genetic characteristics, in this case mitochondrial defects.

Aside from the potential outcomes, some respondents talk about the process by which these types of techniques might become acceptable, mentioning 'desensitisation' to genetic manipulation, or

the setting of a legal precedent which would allow further amendments to the law with less scrutiny. One respondent gives the example of the Abortion Act of 1967 which they believe demonstrate this principle, another discusses the increasing range of conditions for which pre-natal genetic diagnosis (PGD) is now available.

Altering the germline: safety and risk

A total of 160 respondents who disagree with the introduction of the techniques in question 1 express concerns about whether they can be applied safely. Comment on Reproductive Ethics (CoRE) and the Church of Scotland are two of them. Some respondents make general statements about the impossibility of being certain about the consequences, while others specify that they are concerned about the perpetuation of (unknown) side-effects as a result of the germline modification. Views on risk differ between those participants who see the techniques as being likely to result in negative consequences, and those who feel that regardless of the likelihood of the consequences, the severity of side-effects introduced via the germline is so great that any risk is not acceptable. A few respondents give examples of techniques they believe are similar to those proposed and have resulted in negative consequences or side-effects when introduced in human or animal models, for example IVF and cloning.

Alongside the risk of side-effects being passed on, some respondents identify other potential consequences of altering the germline. Some cite the use of mitochondrial DNA to trace matrilineal relationships at the population level, either as a specific feature which would be lost, or as an indicator of the importance of the role mitochondrial DNA plays in maternal relationships.

> "Mitochondrial DNA is identification for the human race. It was how the human race was traced back to Africa. Changing such a vital building block of human development in such a complex being may mean in the future, there may be some unforeseen complications or other disease prevailing as a result."
>
> Individual, Other

Social arguments: three genetic contributions

While the social arguments raised in support of the introduction of the techniques focus on providing opportunities for parents to have healthy children, opponents are primarily concerned with the impact on the child of being conceived in this way. Many respondents who oppose the techniques, including the Anscombe Bioethics Centre, raise the involvement of DNA from a third party as a concern. Some respondents argue that involving the DNA of three people is fundamentally unethical - often citing their belief that Christianity specifies that all children should have one mother and one father. Other respondents believe there is potential for children conceived via these techniques to suffer psychological harm as a result of confusion about their identity. Some cite examples of adopted or donor-gamete born children seeking to contact their biological parents, others feel that the introduction of a third genetic contributor will leave children unable to resolve questions of their own identity. Arguments around whether there are implications for children's identity are covered in more detail in chapter 6.

4.2.3 Other considerations

While the majority of those responding to question 1 expressed their support for, or opposition to the techniques, many issues are raised which are not clearly for or against.

Safety, science, regulation and criteria for application

The most common considerations cited in relation to the techniques overall are specific criteria which respondents think should be applied to decisions about either which technique/s to take forward and/or which to choose in specific cases, should they become available for clinical use, as

mentioned in section 4.2.1 above. Success rate, efficacy or efficiency of the technique is top of the list of criteria mentioned, closely followed by safety. Other criteria include patient choice or appropriateness, medical evidence and advice, cost or value, as well as others such as opening up the techniques to use for anyone or basing decisions around the use of either technique on scientific input or evidence.

A number of respondents stress that regulation would be needed, should the techniques come to fruition. More specifically, there are comments that regulation could or would help prevent the slippery slope, or that the regulator would have an important role in limiting the use of these techniques. Comments about the role of the regulator are analysed in more detail in Chapter 8, which deals specifically with regulation.

In relation to safety more specifically, some respondents are concerned that there is insufficient evidence to prove the safety of the two mitochondria replacement techniques, whilst others talk about the need to compare risks against benefits. Some express a view one way or the other that either the risks outweigh the benefits or vice versa. In addition, a few respondents point out that risks are always present with medical procedures. Many respondents talk about the need for further research, trials or evidence if or when the techniques are taken forward, including a few comments about the need for follow up studies with patients.

> "If shown to be achievable, safe and effective, both techniques have potential to militate against mitochondrial disease. In principle, this is to be welcomed, but some caveats exist.
>
> Current scientific consensus is that mitochondrial DNA (mtDNA) is unlikely to play a role in determining hereditary characteristics; however, understanding of the nature of the interaction between nuclear DNA (nDNA) and mtDNA is far from comprehensive. It has been suggested, for example, that a link exists between mtDNA and cognitive capabilities; caution is, therefore, appropriate.
>
> Some nDNA has effects identical to mtDNA and, if defective, can cause similar illnesses. Mitochondrial replacement therapy will not address this problem. If techniques were developed to counteract these debilitating effects of mutant nDNA it might be assumed that the use of altered nDNA is acceptable, especially if such has already been the case with mtDNA. A separate and full debate on the use of altered nDNA is essential since we know that much nDNA directly affects hereditary characteristics. If mitochondrial replacement is permitted no inference ought to be drawn between it and nDNA manipulation."
>
> Organisation, Church of England: Mission and Public Affairs Council

> "The monitoring of those involved in the first Clinical Trial must be exceptionally careful and long-term - and honest!"
>
> Individual, Other

A number of respondents talk specifically about the function of mitochondria or other scientific aspects of the two techniques.

> "… the mitochondria are the power plants of the cell. This is akin to changing a battery in a laptop for instance, the data does not chance [sic], the layout does not change, the essence of the human is not altered, merely its power source."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

> "I would liken this to replacing faulty spark plugs in a car, it will look and perform the same but the engine will now run smoothly!"
>
> Individual, Other

Others outline their understanding of the science or suggest an alternative approach. There are also a few comments from respondents who are concerned that science should remain at the heart of the decision making on this topic. Scientific considerations are discussed in more detail in the analysis of question 2 (chapter 5).

Ethical considerations

Ethical considerations are covered in more detail in chapters 5 and 6, with the key points mentioned in response to question 1 outlined here.

Concerns over the use of embryos or eggs, and the difference in embryo usage between the two techniques or how others might feel about this, are mentioned by a number of respondents, with some expressing clear concern about the use of embryos or eggs without necessarily explicitly being opposed to techniques, and others saying they are not concerned about this issue. There are also several comments about ethics more generally, and a few on more specific issues such as the lack of consent or choice from the child's perspective.

Some respondents mull over the issue of where the line should or could be drawn with respect to this kind of technique, either around screening or genetic modification itself. Others mention more explicitly the need to consider the risk of a slippery slope occurring, either generally or more specifically with designer babies or commodification, or eugenics. There are also some respondents who point out that these techniques are different to those which would be involved in cloning or creating designer embryos.

Social considerations

Social considerations are also covered in more detail in chapters 5 and 6, with the key points mentioned in response to question 1 outlined here.

In terms of social considerations, various potential legal or insurance issues are mentioned, along with the related issue of a third person's involvement in a child's conception. A number of respondents suggest considerations around the various actors in a potential mitochondria replacement procedure.

With regard to parents, considerations include primarily the need for information provision and close involvement, but also a desire that, should these techniques come to fruition, pressure is not placed on parents to use them. A small number of respondents discuss related issues around the worth society places on mitochondrial disease sufferers or disabled people. Some feel there is a risk that using these techniques would entail losing valuable individuals, respondents interpret the techniques as replacing an individual with mitochondrial disease with another, different individual..

With regard to donors, considerations include comments about the rights and responsibilities of donors, whether their identity should be known or not, and comparisons to gamete or organ donation, as well as a couple of comments about donor availability. These issues are covered in further detail in chapter 7. Considerations around the child include comments about the potential emotional or psychological impacts on a child resulting from these techniques, as well as a number of comments about implications for the child's identity. These issues are covered in more detail in chapter 6.

Other social considerations raised by respondents include considerations of the number of people mitochondria replacement would be applicable to, potential impacts on future generations (including the potential for resulting population increase) and a number of comments about costs

or funding; aside from general comments about who should pay, some people specifically say the NHS should not cover the cost of treatment and others that it should. A few respondents comment on the potential business interest or involvement in offering mitochondria replacement treatments. Others mention alternative treatments, including the suggestion that adoption could be made easier.

Considerations for specific techniques

A number of respondents talk specifically about MST or PNT, or compare the two techniques, with some saying they see little or no difference between the two techniques, for example in terms of ethics. Several respondents say that they think MST could be more publicly or ethically acceptable than PNT, or that PNT is potentially the more controversial of the two because of the use of embryos. Other respondents talk about specific considerations for each of the two techniques, for example whether the use of spare embryos from PNT had been thought about. A few respondents believe that the way the techniques are described is misleading for various reasons.

> "There has been a degree of misunderstanding among the public - these interventions are not a "genetic modification". A genetic modification is when nuclear or mitochondrial DNA sequence is altered - mutated, deleted or inserted. Instead the use of wildtype DNA from a third party is in effect a donation and not a genetic modification.
>
> In other words the human genome is not being modified."
>
> Individual, Researcher

> "I think that it is deceptive to describe this technique as a therapy being offered to prospective parents. The therapy being offered is merely psychological: reassurance that they will not have a defective child. The person affected is the child him or herself."
>
> Individual, Other

> "The term 'mitochondria replacement' is misleading as it is the pro-nuclei or spindles that are being replaced in the host cell rather than the mitochondria being replaced."
>
> Individual, Other

Other references

Many respondents to question 1 make reference to specific supporting information. A large number of these references are personal to the participant, for example information about their knowledge or expertise, where they have a friend, relative or child with mitochondrial disease or similar, or where they themselves are a sufferer of mitochondrial disease. Several respondents make reference to religion or the Bible as part of their response, while others mention politics or the Government (for example the role – or not – of politics in these kinds of decisions), the HFEA, the views of other people generally, or of a specific group or individual. Current legislation on this topic, either in the UK or abroad, is mentioned by a number of respondents, as well as some references to learning from historical experience (for example the progression of scientific knowledge, Thalidomide, eugenics, and the development of IVF). Other specific supporting evidence is referred to by some respondents in the form of relevant research, documents, literature or discussions.

Chapter 5 Question 2: changing the germ line

5.1 Headline findings

1,115 respondents answered question 2, which asked respondents:

> **Q2: Do you think there are social and ethical implications to changing the germ line in the way the techniques do? If so, what are they?**

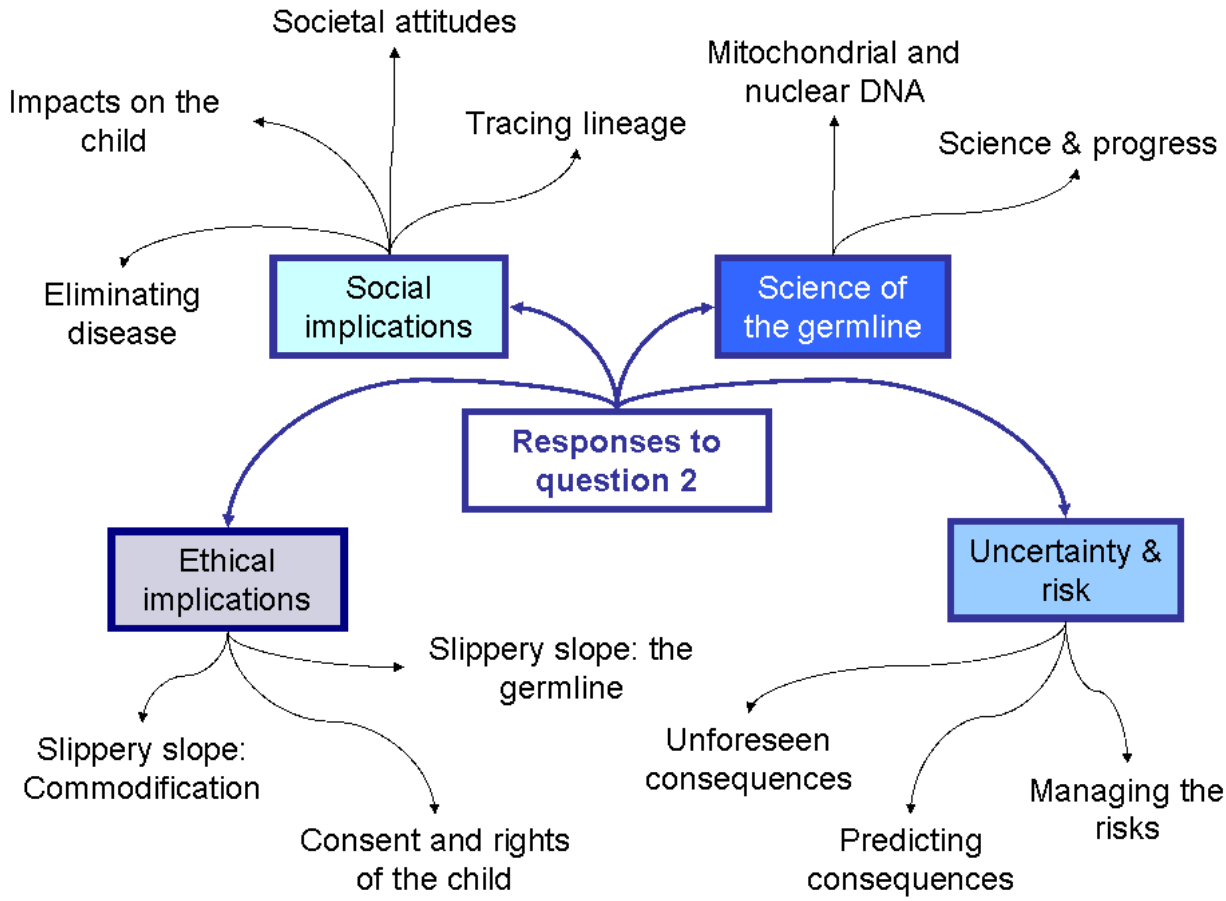
Most responses to this question outline potential implications of changes to the germ line including both negative and positive implications. Some respondents feel the severity of the impacts would outweigh the benefits they believe the techniques will bring; these respondents often cite similar ethical concerns to question 1, or social concerns about the introduction of a third genetic contributor. Others feel that the impacts could be adequately mitigated or are not serious enough to outweigh the benefits - these respondents tend to focus on the social impacts of reducing mitochondrial disease. The implication of changing the germ line is explored by many respondents in question 2, with concerns about the risks of a new scientific procedure, about genetic engineering more generally, and discussion of the role of mitochondrial DNA in the germ line. A number of respondents, including several who identify themselves as mitochondrial disease patients or friends/relatives of patients, state their belief that there are no social or ethical implications of the introduction of the two techniques into clinical practice, or that the only implication is the reduction of instances of mitochondrial disease.

Non-questionnaire responses

In some of the 503 non-questionnaire responses there is mention of changing the germ line. Overwhelmingly these comments are part of a range of similarly worded points which can be found in around 300 emails and letters. The point included about changing the germ line concentrates on uncertainty about the effects on future generations, which respondents consider a concern.

These arguments and others raised by respondents to question 2 are explored in more detail below under the following sub-headings:

Figure 4 Responses to question 2



5.2 Summary of comments

5.2.1 Uncertainty and risk

The paragraphs below describe the concerns of respondents who believe there are negative consequences of the techniques; in many cases respondents describe the scale and likelihood of the perceived consequences, while a few respondents argue on principle that any risk to future generations is unethical. They feel that the act of taking a decision which imposes these risks is unethical, as the choice is removed from the future individuals - this argument links closely to questions of consent explored under Ethical implications below (section 5.2.1).

Unforeseen consequences

The most common issue raised by respondents in relation to the germline is a concern that there may be unforeseen consequences of the proposed techniques, which would then be perpetuated in future generations. Often respondents are concerned with the scale of consequences - they see the potential consequences as too large or dangerous to be acceptable, even if they are very unlikely. Many refer to the idea that many generations would be affected, seeing this as frightening or inappropriate; others describe the potential germline change as being ‘uncontrollable’ suggesting that:

> "… we simply do not know what harm we may be doing, and such harm may extend indefinitely to many generations."
>
> Organisation, Anscombe Bioethics Centre

Another variation on this theme is the idea that consequences may not be discovered until several generations have passed, by which time it may not be possible to contain the germline change, or even to identify all carriers.

While most respondents who comment on unforeseen consequences cite this as a general principle, a few respondents give examples of particular implications they see arising from use of these techniques, often describing these as unintended consequences. Some of these respondents believe there may be negative health impacts of the techniques, discussing issues such as the combination of mitochondrial and nuclear DNA when the two are inherited from different parents. Others talk in general terms about unpredictable psychological impacts on children born via the techniques and their families (discussed in more detail below).

Predicting consequences

Other respondents discuss the level of risk - they are concerned that we are not able to adequately assess the potential consequences of using these techniques in clinical practice. For some of these respondents our inability to determine the consequences is seen as inherent, and they describe their feeling that the consequences of genetic modification are 'unknowable'. Others argue that the consequences cannot be known until the techniques are implemented in humans, and even then not necessarily in the first generation, for example:

> "The Council noted a number of ethical and social implications, including that using these techniques might create health risks to the resulting child and his or her descendants, particularly as it will not be possible to exhaustively assess the safety of the procedures until several generations have been born using them (paragraph 4.37)."
>
> Organisation, Nuffield Council on Bioethics

A few respondents who believe that negative consequences may emerge in subsequent generations suggest that this would mean monitoring of both children born via the techniques, and their subsequent offspring for several generations.

Managing the risks

Although most respondents who posit unforeseen consequences of the two techniques believe this should prevent them being authorised, some cite potential impacts and then suggest ways in which they can be mitigated. This includes procedural suggestions, such as ensuring that the mitochondrial donor has similar genetic heritage to the intended mother (i.e. has similar mitochondrial genes). Others give suggestions for managing the social consequences for the child, most often recommending that the child should be made aware of the circumstances of their birth, with information given in a considered and sensitive way.

One suggestion made by some respondents is that ongoing monitoring should include subsequent generations, however there are a number of respondents who express concern about the consequences of such monitoring. As described below, some feel it will lead to stigmatisation of the individuals concerned, or that they will feel 'different' because of the requirements of monitoring.

There are also a few respondents who discuss the concept of uncertainty and risk, suggesting that fears of the uncertain and unknown are common when novel technologies are posed, and should

not necessarily prohibit their progress. This debate is picked up again in the Science section 5.2.4 below.

5.2.2 Social implications

Eliminating disease

There are 68 respondents who specify that they believe the benefits of the techniques outweigh any social or ethical implications. The majority of these respondents, including a number of respondents who identify themselves as having personal experience of mitochondrial disease (patient or friend/relative), suggest that the elimination or reduction of instances of mitochondrial disease is a social benefit, offering benefits to children and families, or more generally as an improvement to health at a population level. As in several of the questions, a few respondents emphasise the severity of mitochondrial diseases, and the psychological impact of hereditary disease when weighing up potential benefits and disadvantages of introducing the techniques.

> "If I can prevent the inheritance of mitochondrial disease by altering the gene line then this is far preferable than for the risk and fear of disease staying in my family forever."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

A number of respondents to question 2 discuss benefits they perceive for future generations because of the modification of the germline. They argue that because the mitochondrial defect which causes disease is removed from the germline subsequent generations are also freed from the potential to inherit the disorder, and that this makes the techniques an ideal response to the problem of heritable disease.

Societal attitudes

A common issue mentioned in response to question 2 is how the introduction of the techniques to clinical practice might affect attitudes towards different groups, particularly those born as a result of the technique and sufferers of mitochondrial and other disorders. There are 56 comments on social attitudes towards those conceived via the techniques, with a range of views expressed. Some respondents, including the ProLife Alliance, suggest that those 'treated' could be ostracised or discriminated against for being 'created in a lab', or because of the third genetic contributor. Many of these respondents suggest that the requirements for those born via the techniques to take part in medical monitoring will contribute to them being treated as 'guinea pigs'. This argument is often associated with ethical concerns about the motivations of parents, clinicians and scientists in implementing the techniques. In contrast, others note that such prejudices do not seem to have arisen in relation to artificial reproductive techniques such as IVF, and feel that it is not a major concern. A third point of view comes from those who feel that discrimination may be an issue in the short term, but will ultimately be overcome:

> "Socially, there may be short-term issues with the interaction of treated with non-treated, and with those who opposed use of the techniques. However, that should not prevent us from moving forward with them. 'Test tube babies' do not appear to have met with any significant stigma over the long term, and I don't see why these babies would either."
>
> Individual, Other

A related issue raised by a similar number of respondents is whether making these techniques available will have an impact on attitudes towards those with disabilities (including mitochondrial disease). Some respondents argue that the techniques amount to preventing the births of people with mitochondrial disorders, effectively discriminating against them. A number of these respondents note a link to wider debate about perceptions of disability in society, and of disabled people themselves:

> “My only concern about alterations in the germline is that it reifies genetic 'normality', and creates an anti-disability narrative that will encourage people to view themselves or others as 'abnormal'.”
>
> Individual, Researcher

Respondents are concerned that there will be increased levels of intolerance for those with disabilities, especially mitochondrial disorders, with disabled people questioning why the proposed techniques were not used to prevent their disability, and by inference, their birth as disabled individuals. Others see a potential connection between the proposed techniques, decreased tolerance of genetic defects and increased acceptability of other genetic modification techniques and the ‘designer baby’ concept discussed in question 1.

A smaller number of respondents argue that rather than encouraging discrimination against those who are treated, introduction of the techniques will lead to negative attitudes towards those not treated. They argue that once the techniques are available:

> “Parents who do not comply with such techniques will indubitably be made to feel irresponsible by scientists, medical personnel, society at large...”
>
> Individual, Other

One or two specifically mention potential problems they see arising within families where some children have been conceived by the techniques, while others have not. Some respondents expand on this theme, suggesting that parents may be pressured into using the techniques either unnecessarily, or against their will, because of a perception that it would be irresponsible not to.

Impacts on the child

As in most questions throughout the consultation, many respondents comment on the introduction of a third genetic contributor, expressing concern about the psychological impact of a third ‘parent’ to a child conceived via the techniques - these issues of identity are covered in detail under question 3 (Chapter 6). A number of respondents take the opportunity to express their concerns about the psychological or emotional impact on children conceived via these techniques, while a similar number express their belief that the wellbeing of any child would be improved.

A few respondents raise specific concerns about identity issues relating to the germline. In particular there are concerns that kinship and family may continue to be disrupted in subsequent generations.

> “Families may not accept future generations as truly related if the germ line is changed, I would certainly be unsure if a child was truly my child if they had donor mitochondria.”
>
> Individual, Other

Tracing lineage

Mitochondrial DNA can be used to trace the genetic heritage of individuals, and of populations on an historical timescale - some respondents, including the National Gamete Donation Trust, make reference to this in question 2, noting that mitochondria replacement would confuse this genetic ‘family tree’. Most respondents who mention this issue describe it as a minor issue which should not prevent the techniques being used, and a few suggest that steps could be taken to record the identity of the mitochondrial donor in some way to mitigate the impact. One or two respondents raise the issue of criminal investigations using DNA evidence, and question whether mitochondria replacement could affect this.

5.2.3 Ethical implications

As in question 1 a number of respondents (158) express concerns about the use of embryos, particularly in the case of pro-nuclear transfer. These arguments are described above in section 4.2.1. Other arguments common to question 1 and explored in more detail there are those relating to 'playing God' and the ethical imperative to intervene.

Consent and the rights of the child

A number of respondents in question 2 discuss the concept of whether the modification of an embryo or egg (no distinction is made in this context between the two techniques) could be allowed to take place without the consent of the ensuing individual. There are two strands to this argument, firstly that in the case of the parents who use the technique to conceive, they have made that choice on behalf of the child. As one respondent puts it:

> "I feel very uncomfortable with the prospect of making such decisions without the consent of the individual concerned. There's no 'going back' if someone finds the background to their conception difficult."
>
> Individual, Other

Others refer to the importance of informed consent in scientific experimentation, and in medicine more generally - they argue that as it is impossible to gain the informed consent of the 'child' before the procedure is carried out, it is unethical. In contrast, a few respondents note that parents make decisions on behalf of their children as a matter of course, for example the Nuffield Council on Bioethics note that:

> "The issue of consent has been raised in the context of germline therapies, given that no child born from such procedures can have consented to them. However, **this issue is common to all reproductive technologies, as well as other prenatal and childhood medical intervention** (paragraph 4.38)."
>
> Organisation, Nuffield Council on Bioethics

The second strand of this argument is that once the change has been made to the germ line, it will be passed on - in effect the children conceived by the technique are not able to choose whether or not they pass on the technique to their children. Again, an opposing view is argued by a small number of participants who question whether this consent is relevant, given the impossibility of ever acquiring consent from future generations about any decisions taken on their behalf.

The argument as stated here focuses on the principle of consent of the individual to the changes; an alternative formulation focusing on the practicalities of making decisions for future generations is described above under uncertainty and risk, (section 5.2.1) where some respondents questioned whether individuals have the right to expose future individuals to particular risks.

Slippery slope: commodification

The 'slippery slope' by which the introduction of these techniques could lead to others is a common theme throughout the consultation, with respondents expressing a range of concerns about potential outcomes. There are 150 respondents to question 2 who raise concerns about the introduction of techniques which modify the germline opening the door to parents able to select for characteristics rather than medical need. While some respondents argue by comparison between 'selection' for medical purposes and selection for 'trivial' characteristics, others argue from the principle that any selection on the part of the parents crosses a line.

> Once more the new techniques ignore the basic principle of what is meant by uniqueness in the individual. It opens the way to the normalisation of genetic modifications. In time it is inevitable that government will begin to interfere in the decision making process about what forms of offspring will / will not be acceptable. A dangerous threshold will have been crossed and the long term outlook is unknowable.
>
> Organisation, Scottish Council on Human Bioethics

In contrast there are some respondents, including the Muscular Dystrophy Campaign, who state their disagreement with this argument, typically because they feel that sufficient steps will be put in place to prevent such a shift from one purpose to another. One or two suggest that because the proposed modification to the germline is limited to mitochondrial DNA, this argument is less applicable:

> "Firstly, these techniques limit germline manipulation to genes of the mitochondria, which are involved solely in programming the functions of these organelles."
>
> Organisation: The Wellcome Trust

Slippery slope: the germline

Another variation on the slippery slope argument common in question 2 focuses on a perceived relationship between germline modification and eugenics, suggested by 70 respondents. Many respondents who mention eugenics do so without giving detailed arguments, and may be using the term simply to denote all genetic modification or engineering. However others argue specifically that the process of 'selecting' against a particular genetic trait is the basis for their concern:

> "We are also concerned that changing the germ line will result in the normalisation of genetic modification in humans. While it is admirable to seek to cure disease, we are concerned by the eugenic undertones of any technology that allows doctors and parents to 'rank' one embryo above another."
>
> Organisation, Christian Concern

Another discussion specific to question 2 is whether once germ line changes are introduced for mitochondrial DNA, it will gradually become possible for nuclear DNA changes to be introduced. This debate is brought forward by a small number of respondents, with a few arguing that the difference between the two types of DNA is clear, and one will not lead to the other, while a similar number argue that the difference will not prevent a move towards more techniques being available.

5.2.4 The science of the germline

There are a number of respondents who take the opportunity in question 2 to discuss aspects of the science around germ line modification which they feel are pertinent to the social and ethical implications of the techniques. Typically these points are made by smaller numbers of participants than the main ethical and social arguments described above, and are less commonly associated with an expressed preference for or against the introduction of the techniques into clinical practice.

Mitochondrial and nuclear DNA

Several respondents talk about the role of mitochondrial and/or nuclear DNA, particularly in relation to the question of identity. The relationship between mitochondrial DNA and identity is covered in detail in chapter 6, dealing with question 3. The most common of these comments, made by the Academy of Medical Sciences and the British Fertility Society among other organisations and individuals, is that the nuclear DNA (and some respondents say the genome) is not affected by the two mitochondria replacement techniques, with some linking this to other comments such as the fact that they therefore have no ethical or social concerns. Other

respondents give conflicting views about mitochondrial DNA, with a number of respondents stating that it does not determine identity or traits and somewhat fewer stating that they think it does or might. The function of mitochondria is the subject of some responses, in particular from respondents who say that the mitochondria are just for energy production and that replacing them would be like changing batteries, although others believe they play a more important role or that we do not fully understand their role.

> "I see this essentially as changing the batteries that power the fertilised egg, embryo and ultimately, person but without having the ethical impact of alteration of the expressed DNA."
>
> Individual, Other

> "If mitochondria are so trivially put as powerhouses of the cell why are the consequences so dire when they do not work?"
>
> Individual, Researcher

A number of respondents, including the Wellcome Trust, talk about the small amount of DNA involved in mitochondria replacement, whilst there are a couple of concerns that even this would be too much or have too much impact. There are also a small number of comments about the origin of mitochondrial DNA, specifically that they were originally symbiotic bacteria living in host cells.

> "Mitochondria are best viewed as separate organisms living in cooperation with host cells. They are much like the gut bacteria without which we couldn't live a healthy life, there are increasingly numerous examples of organisms that cannot live without one another - plant roots and soil fungi for example."
>
> Individual, Other

Other comments about mitochondrial DNA are varied and include observations about the importance of mitochondrial DNA for sustaining life, the number of different lines of mitochondrial DNA and a range of other observations about the science surrounding mitochondrial DNA and the implications of mutations or replacement. In addition, there is a focus on the female or maternal line, with respondents saying either that the proposed techniques would only impact the female germ line, or that they would make tracing lineage through the female line more complicated. A few respondents talk about more technical aspects of mitochondria replacement; there are some suggestions about specific sources for the donation such as using the father's mitochondria, those of a close friend or relative, or mitochondria from the same haplogroup as the mother. There are also a small number of comments suggesting that the faulty mitochondrial DNA should be kept for posterity.

Respondents make a range of other comments about nuclear DNA. A few respondents say that DNA mutates naturally anyway over time, a process they see as analogous to the deliberate change introduced by mitochondrial transfer; in the main these comments focus on the argument that these techniques would be speeding up that natural process, although one respondent is concerned that evolution is based on abnormalities and that we should not "deny ourselves the chance to grow and show the best of ourselves". Others discuss the natural mixing of DNA that occurs through reproduction, often accompanied by the view that this makes the process of mitochondria replacement less significant because it is seen as replicating a natural process.

> “Changing the germ line is the very essence of sexual reproduction - the fact that mixing genes can result in a wider variety of characteristics is advantageous to a species. Essentially, it's a very natural thing.”
>
> Individual, Student

There are also a small number of other comments about nuclear DNA, for example around its function, our current knowledge, and the influence of environmental factors on gene expression.

Many respondents talk about the germ line more generally, including the idea of altering it. There are equal numbers of respondents who say it is ok to alter the germ line (for example because this is a positive or purely functional alteration) and that it should not be altered (for example because of unknown consequences or the crossing of an ethical boundary). A few respondents comment that the germ line would not be significantly changed by these techniques. Others discuss specific outcomes they speculate could occur as a result of MST or PNT, for example that the germ line could reduce in diversity, or that the mixing of mitochondrial DNA could cause a genetic advantage or be beneficial, although others say that they think the germ line would simply be repaired rather than enhanced.

Other comments about the germ line include a variety of positive and negative comments about changing the germ line, the statement that we are all related if you go far enough back, that this would be a new step for science because it involves altering the germ line, and comments about the long-term (i.e. multi-generational) changes brought about by alterations to individuals through these techniques.

Science and progress

The nature of science and scientific progress is commonly cited in response to question 2, either specifically in relation to mitochondria replacement techniques or more generally. By far the most popular comment in this respect is that reducing mitochondrial disease is a positive thing, with many of these respondents referencing some of the social benefits already cited in response to question 1. Other comments about scientific progress in relation to mitochondria replacement include: this is natural progress or that scientific progress overall is a function of being human; the possibility of doing something does not mean it should automatically happen or further progression of these techniques requires caution; and progress has gone too far to stop now. There are a few other observations on where these treatments sit in relation to overall scientific progress in this field.

> “With the introduction of the treatment there may be a rise in research interests in this area, leading to safer, cheaper treatments, many targeting conditions which have not yet been treated. The treatment may even allow us to clear up any ethical/social concerns regarding germ line engineering of human nuclear DNA in germ line cells.”
>
> Individual, Student

> “Changing the germ line is a step change beyond other techniques currently used for infertility treatments.”
>
> Individual, Non-questionnaire response

> “This sort of gentic [sic] modification is merely an extension of medicine beyond most people's intuitive comfort zones when it comes to trusting and understanding science.”
>
> Individual, Student

Some respondents comment specifically on the nature of these two techniques, including comments that this could or would be a one-off or single generation treatment, or that it could be restricted to male births. Other respondents express overall objections to fertility treatment, or in several cases talk about preferable priorities for investment such as other treatments or cures for mitochondrial disease.

Concerns that current scientific understanding is limited, for example about the function of mitochondrial DNA, are raised by some respondents, including Comment on Reproductive Ethics (CoRE), alongside other comments on the need for further evidence or research, for example specific suggestions for trials or follow-up studies.

> “Should mitochondrial material, and the use of a donor cell wall, have greater purpose than is currently known, we are in danger of harming future generations unless there is a long and rigorous process of testing implemented.”
>
> Individual, Student

There are some comments about the trust or lack of trust in scientists and scientists’ motivations, for example concerns that scientists may not always undertake research for the right reasons or more overt expressions of mistrust (some respondents suggest scientists are ‘arrogant’), as well as one respondent who says that they do trust scientists. Other respondents discuss the nature of medicine or science, for example stating that its purpose is to treat illness or to benefit humankind, although these statements are used in different ways to either support or oppose the two techniques, for example a number of respondents say that the use of embryos goes against the idea of benefitting humankind. A small number of suggestions for how science should balance with ethical, religious and scientific considerations are also made; some respondents would like to ensure that ethical considerations based on religious views have an important place in the debate, whilst others would like the debate to focus on science and ethics in purely secular terms.

Finally, there is a range of other comments about either the science of these techniques or overall science more generally. For example, some respondents question how effective these techniques would be and others talk about the need to weigh up all considerations for any new technique on a case-by-case basis.

Chapter 6 Question 3: implications for identity

6.1 Headline findings

1,084 people responded to question 3 of the consultation which asked:

> **Q3: Considering the possible impact of mitochondria replacement on a person's sense of identity, do you think there are social and ethical implications? If so, what are they?**

Most respondents make specific comments about how they think mitochondria replacement may have an impact on a person's sense of identity, or why they believe this impact will be limited.

Where respondents state that they believe there will be implications, most describe these. Their comments cover the genetic make-up of children born as a result of mitochondria replacement, the potential issues around children's relationship to their mitochondria donor, and the potential impact on these children's emotional or psychological well-being. A handful of respondents say they believe there will be implications but make no further comment.

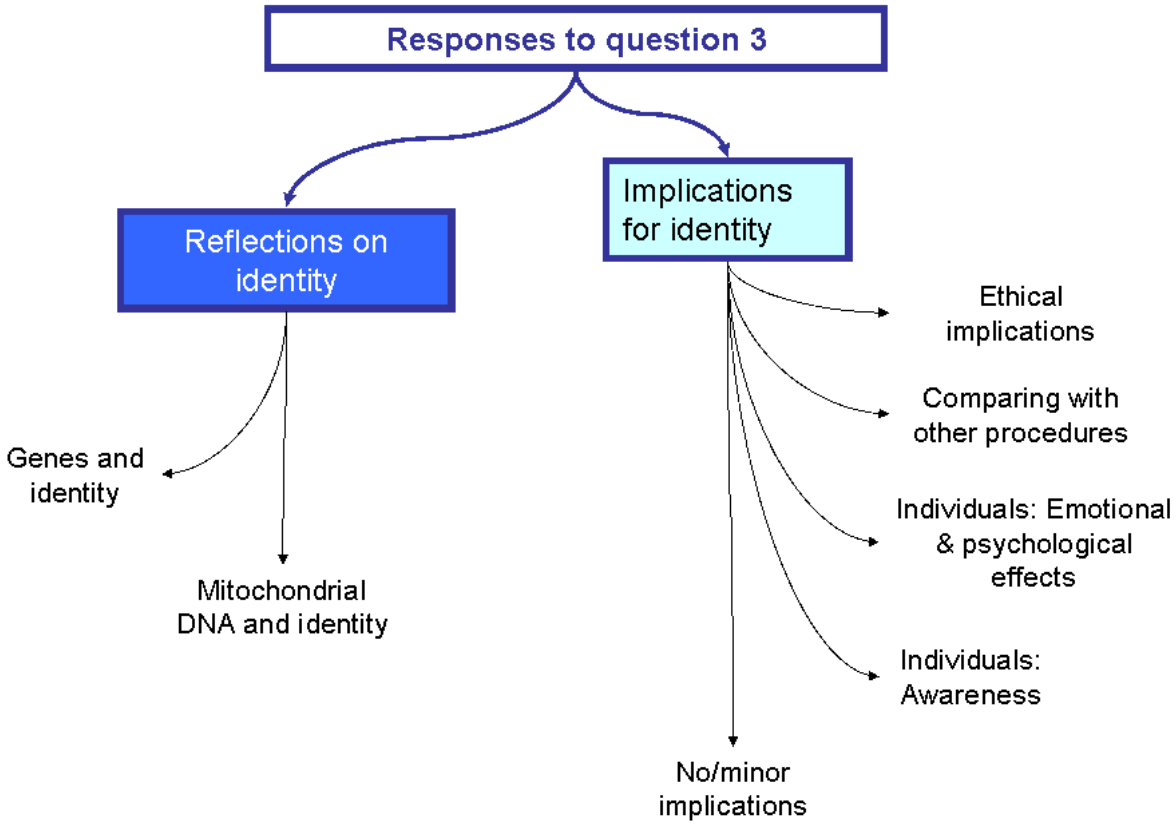
Where respondents indicate that they believe there will be no implications, they tend to argue that mitochondrial DNA does not determine a person's identity. Many suggest too that mitochondria replacement is unlikely to have greater implications than currently used procedures including egg and sperm donation. A total of 38 respondents merely state that they do not think there will be implications.

Non-questionnaire responses

Comments about possible implications on identity are also made in some of the 503 non-questionnaire responses. Most of these comments are made in letters and emails that follow a similar structure and make a series of similarly worded points. One of these points is a concern about the impact of mitochondria replacement on the well-being of children conceived in that way, who respondents believe may suffer psychological damage as a result of it. Also, the idea that three (or four) people would be involved in the conception process is often cited as a concern, although not always in relation to identity.

These arguments and others raised by respondents to question 3 are explored in more detail below under the following sub-headings:

Figure 5 Responses to question 3



6.2 Overview of comments

6.2.1 Reflections on identity

Question 3 inspires some respondents to reflect on the concept of identity and how personal identity relates to individual genetic make-up. Two broad themes characterise this discussion: whether or not mitochondrial DNA is significant to identity and whether or not a person's genes influence or determine identity at all. These two discussions are described in turn below.

The relationship between mitochondrial DNA and identity

When respondents comment on the relationship between mitochondrial DNA and identity, they often argue that this relationship is either negligible or absent. Some 100 respondents including several who identify themselves as mitochondrial disease patients, or friends/relatives of patients, say they believe that an individual's personal characteristics are not affected by their mitochondrial DNA, but rather depend on the genetic information in the nuclear DNA. This view is also expressed in responses of various stakeholder organisations including the Association of Clinical Embryologists (ACE) Executive Committee and the British Medical Association.

> "Identity, if it rests anywhere in a person as an embryo, rests in the genetic inheritance in the parts of the DNA that affect personality, traits etc, not their mitochondria."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

The quantity of mitochondrial DNA relative to the quantity of nuclear DNA is discussed by 63 respondents. Most of these emphasise that mitochondria contain a very small part – some mention 1% and others cite smaller percentages – of a person's genetic information. Some respondents also reflect on the nature and function of mitochondria and mitochondrial DNA. Most of these say

that mitochondria are there to help cells produce energy, with several respondents likening mitochondria to batteries in cars or other tools. Respondents using these lines of argument generally think that the quantity and/or purpose of mitochondrial DNA suggest that it is unlikely that mitochondrial DNA has implications for identity.

> "MtDNA, which is the only type of genetic material altered by these techniques, encodes just 37 of the 22,000 human genes, or less than 0.002 per cent of the total."
>
> Organisation, Wellcome Trust

A small number of respondents take a different view on the significance of mitochondrial DNA in the constitution of an individual's identity. Their comments emphasise that we do not know sufficient to be certain that mitochondria are relevant to energy generation alone and that the possibility remains that the genetic information in mitochondrial DNA does affect a person's traits.

> "In reality our understanding of the amount, influence and purpose of mitochondria is still limited and conclusions such as this need to be treated with caution."
>
> Organisation, Christian Medical Fellowship

The relationship between genes and identity

For some respondents a more fundamental question about identity needs to be addressed in relation to this discussion: to what extent is an individual's identity influenced or determined by their genes? Some respondents emphasise that identity is a complex concept which may have genetic as well as environmental and circumstantial components.

> "Identity is a complex issue, and is based on a myriad of factors, of which a person's biological origin covers only a handful."
>
> Individual, Other

Several respondents argue that the extent to which individuals' sense of identity is affected by their genetic make-up, or their understanding thereof, is a personal matter and will vary between people. Some reflect on what they see as the struggle that many young people and adults experience trying to make sense of their identity in today's society, regardless of their family situation or genetic heritage.

> "All people search to establish their sense of identity. All people struggle with whatever it is that has made them."
>
> Individual, Other

About 75 respondents discuss specifically whether it is one's genes (nature) or one's upbringing (nurture) that most influences their sense of identity. The majority of these respondents express the view that identity is predominantly formed during life, and many respondents highlight the role of parents in providing the environment in which a child grows up, saying this is a prime factor affecting their sense of identity. Organisations making this argument include the Humanist Society Scotland and PROGAR. A few respondents cite specific examples to underpin their arguments, such as two genetically identical twins growing up to be different individuals with their own distinct identities.

In contrast, a few respondents emphasise the role of genetic information in shaping a person's identity, stating it is this that makes them unique human beings. Others consider that neither genes nor upbringing are dominant by definition and that this uncertainty should be acknowledged.

> “However, this brings us back to the long-debated Nature vs. Nurture argument. It is difficult to say how much of a person’s identity is influenced by their genetics, and how much is influenced by their upbringing.”
>
> Individual, Student

6.2.2 Ethical implications

In responding to question 3 most respondents concentrate on social rather than ethical implications. Respondents who do comment on ethical implications often reflect on the proposed techniques in a general fashion. For instance, some argue that the techniques are interfering with nature and some suggest that they cross a boundary and set a precedent for other more controversial techniques. These and other discussions about ethical implications of mitochondria replacement in general are discussed in detail in the chapters on questions 1 and 2.

Several respondents raise an ethical implication specific to identity. These respondents emphasise that children born as a result of mitochondria replacement will not have been able to give their consent. This is generally followed by concerns that these children may experience this as a burden during their lives.

> “This procedure also poses the ethical issue of changing a person's identity without his or her consent.”
>
> Individual, Other

A different but related point is made in some of the 53 responses that cite the use of embryos in PNT as a particular ethical concern. Several respondents reflect on the impact of this on the resulting individuals' identity or well-being more generally. They are concerned that some people may feel a sense of guilt or unworthiness when they realise that their conception has been aided by a process that involves the creation and destruction of embryos. A few respondents speculate about the individuals that might have been born if the embryos used had been allowed to develop, and sometimes suggest that these could have become 'better' individuals, leaving the child with a greater than usual sense of having to make up for the potential achievements of those not born. They see this as an additional burden on children born as a result of PNT.

> “So quite aside from the issue of parenthood, they will also have to battle with the idea that two distinct human lives were destroyed in the creation of their life.”
>
> Individual, Other

A small number of respondents present views specifically on the ethical trade-off between health and identity, discussing whether one of these should prevail. A few argue that a non-compromised sense of identity should be favoured, whereas most of those reflecting on this trade-off prioritise the individual's health.

> “I accept that some individuals will have a different view, but cannot see that such concerns would outweigh the benefits of being born healthy!”
>
> Individual, Personal experience of egg, sperm or embryo donation or donor conception

6.2.3 Social implications

No implications or minor implications on identity

There are some 130 respondents, including the British Fertility Society, who specify their belief that mitochondria replacement will have little or no social or ethical implications for a person's sense of identity. Respondents who identify themselves either as being affected by mitochondrial disease or as being a friend or relative of someone affected by mitochondrial disease often take this view. Roughly half of those who do not foresee any implications explain their view with references to mitochondrial DNA, stating that this is considered to be insignificant compared to nuclear DNA. Some emphasise that the nuclear DNA of individuals conceived with the assistance of mitochondria replacement would be from both their parents, and that this is what will constitute their genetic make-up. Paragraph 6.2.1 above covers respondents' views on the significance of mitochondrial DNA in more detail.

> "I think the implications of having mitochondrial DNA from a donor as well as nuclear DNA from two parents are interesting, but certainly not problematic."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

Several respondents explain that they have come to the view that there are no implications on identity by reflection on their own situation or sense of identity. Some comments concentrate on the respondent's genetic relationship with their parents, others attribute great importance to the family environment they grew up in. One comment is from a donor-conceived person, who states that from their personal perspective there are no implications for identity:

> "I don't see any implications for identity, and I say this as a donor-conceived (DC) person who believes that genes help to make us who we are."
>
> Individual, Personal experience of egg, sperm or embryo donation or donor conception

> "From a personal perspective, I think if I knew I had different mitochondrial DNA I would see it as an additional part of my identity, rather than confusing my identity. I would still see the people who gave me my nucleic DNA as my biological parents, rather than the mitochondrial donor."
>
> Individual, Other

Similarly a few respondents relate their response to question 3 to personal experiences with mitochondrial disease, generally arguing that they do not consider mitochondria replacement to greatly affect an individual's sense of identity. The Muscular Dystrophy Campaign engaged with families affected by a mitochondrial disease and found that they were not concerned that the proposed techniques would have identity implications:

> "When families affected by a mitochondrial disease were asked this question none of them had any concerns that mitochondria replacement could have an impact on their future child's sense of identity."
>
> Organisation, Muscular Dystrophy Campaign

Respondents sometimes emphasise that an individual's environment is important in mitigating the potentially negative implications on their sense of identity. One element of this, according to respondents, is the provision of accurate information to individuals conceived with the help of mitochondria replacement techniques. Some respondents specify that children should be told about the impact of mitochondrial disease as well as the process of mitochondria replacement.

This is usually seen as a task for the parents, and several respondents highlight that they believe children should be made aware of this from an early age.

Another element touched upon by multiple respondents is the quality of close family relationships. Respondents believe parents need to be loving, understanding and open, and that this should prevent children born with donor mitochondria from struggling with their sense of identity.

> "As long as there is a loving family who are willing to explain and help the child underdstand [sic] and the child is disease free and can live a healthy life then there should not be an issue with a person sense of identity."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

Many respondents who think there will be limited or zero social and ethical implications on identity make comparisons with other, existing procedures. Respondents make rather varied suggestions as to which procedures offer the most appropriate comparison, from blood donation to egg donation to adoption, but their overarching argument is often similar: that the identity implications of mitochondria replacement will be no different from those of the other procedure. For many respondents this equals a view that implications will be minimal, although some respondents feel different about this. Paragraph 6.2.4 below covers the detail of the comparisons respondents draw.

> "The question of identity is often overinflated. It is the same argument as adoptive children, step-children, mixed-race children, donated sperm or egg children - it is about the individual and how this acceptance or rejection becomes part of who they are."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

> "Once the novelty of the technique itself has subsided, we do not believe properly informed recipients should have significant identity issues."
>
> Organisation, AMRC and Genetic Alliance UK

Implications for the individual: awareness

A total of 105 respondents reflect on the need for individuals born after mitochondria replacement to be aware of this, and to understand it as fully as possible. There is not much debate about whether individuals should be told about their genetic make-up; virtually all comments are in favour of sharing this information with children. The topic of child awareness is addressed by several respondents who identify themselves as mitochondrial disease patients or friends/relatives of patients, as well as respondents who indicate that they have personal experience of gamete donation. It also features in responses from various stakeholder organisations including the National Gamete Donation Trust and PROGAR.

Many respondents believe that if parents are open with their children about the unusual way they have been conceived, children will not be troubled about their identity, or at least not more than children conceived in more traditional ways. Where respondents specify this, they generally believe that the information should be presented to children from a young age. Others specify that they believe parents should always be sensitive to their child's ability to understand the information and pitch the message accordingly. A few respondents highlight the other side of the coin and say that children will be more likely to encounter identity issues if they do not receive clear information early in life.

> “I can imagine that if it was not explained clearly to either the parents or the children it could produce issues later in life.”
>
> Individual, Other

A small number of respondents discuss the benefits of guidance and support available to parents of children conceived with the help of mitochondria replacement. They believe that this will help ensure that parents feel confident and sufficiently informed to talk to their child.

> “The debate around these techniques should be informed by professional bodies so that any children born from these techniques understand that they are just as much their parents' child as if they had their mother's mitochondria.”
>
> Individual, Other

A few respondents express concern about parents’ willingness or ability to inform their child of the process that led to their conception, with one respondent stating that this is a common problem in families with donor-conceived children. Another respondent raises the concern that individuals with mitochondria from a donor might not inform their future partners about this, which might have consequences for offspring further down the line. In the opinion of another respondent such situations are unlikely to arise, as the need for medical supervision will ensure that the individual is aware.

> “Experience has shown that few donor conceived people have been told the truth about their conception by their heterosexual parents and doubtless fewer still will be told the exact nature of the preimplantation changes made to their embryo form at the laboratory stage.”
>
> Individual, Personal experience of egg, sperm or embryo donation or donor conception

Implications for the individual: emotional and psychological

Many respondents, 228 in total, comment on the emotional and/or psychological implications mitochondria replacement could have on children resulting from the proposed techniques. Almost all of these respondents, including Comment on Reproductive Ethics (CoRE), think that there will be implications, and generally suggest that these would be detrimental to the individual. Most of these respondents, although not all, have stated their opposition to mitochondria replacement in response to question 1.

The most frequently cited reason for children to suffer emotional or psychological damage is confusion over their mitochondria donor, specified by many respondent as their ‘third parent’ (with numerous responses also citing a potential ‘fourth parent’ in relation to pro-nuclear transfer). Respondents highlight issues relating to uncertainty about who the mitochondrial donor is, but more often explore how the existence of the donor might complicate a child’s relationship with its parents. There are, among others, some 25 responses using similar or identical words to describe how children conceived with the help of mitochondria replacement could be affected emotionally:

> “Children born as a result of either of these processes may be confused or distressed in their understanding of who their parents really are.”
>
> Individual, Other

Another concern that many respondents mention is the likelihood that children will feel different because of their unusual genetic make-up. Respondents worry that children will experience difficulty fitting in, either within their family or among peers who have been conceived in more traditional ways. Some specify that children might perceive themselves as a ‘freak’ or a ‘science

experiment' and that this may come with shame or low self-esteem. A few respondents emphasise that children have not been able to consent their conception through mitochondria replacement and suggest this can be an additional emotional burden. Several reflect on how they would personally feel and express their presumed disquiet in a variety of qualifications:

> "I would feel disheartened and irreversibly dehumanised to realise that I am not biologically connected to my fellow humans around me in the same way that they all are to each other. My life would be heavily coloured by bitterness towards my parents and the doctors who had in part created me."
>
> Individual, Other

To some respondents, an important component of children's potential emotional and psychological problems lies in the use and discarding of embryos as part of the pro-nuclear transfer technique. They are concerned that children will experience something they describe as 'survivor guilt' or 'survivor syndrome': a sense of guilt about the embryos destroyed in the process of their conception. Some respondents add that this may make the individual feel worthless, or that it will create pressure to live up to expectations of being the 'chosen one' among embryos that were not allowed to develop. A number of respondents qualify a child born through pro-nuclear transfer as a 'clone', stating that this will cause severe identity problems.

> "There could also be guilt about any other embryos that have not survived the process and resentment of the fact that the person may not have been acceptable to his/her parents without the replacement."
>
> Individual, Other

The potential impact of mitochondria replacement on an individual's sense of identity within their family, and vis-à-vis parents and siblings, is discussed in many responses. There are many aspects to this discussion, some of which only appear in a small number of responses.

As mentioned above, respondents often foresee emotional or psychological issues in the child's realisation that there is a mitochondria donor who contributed to their genetic identity. Although some respondents believe children will perceive the mitochondria donor as a (third) 'parent', others refrain from this assumption, or reflect on their uncertainty on the matter:

> "Will they think of it as three parents? Or just two parents who went to the DNA store and bought some better DNA than their own DNA."
>
> Individual, Other

Respondents believe that the involvement of a mitochondria donor will complicate the relationship between children and their parents. Some feel that family relationships depend on full genetic kinship, and are weakened if mitochondria are acquired from a donor. This, according to respondents, could make children feel inadequate or excluded from the rest of their family.

Another aspect mentioned in various comments is the potential for children to feel that their parents were not ready to accept them in their 'natural' capacity and preferred to artificially improve them through mitochondria replacement. In some comments, respondents conclude that this means parents were more concerned with their children's health or viability than with their 'innate' quality or identity. Another comment suggests that the interference with the child's conception may bring a child to sense that the parents were unhappy with their own identity:

> “They could sense that the parents who wanted them did not want to conceive them naturally, as the parents themselves felt to be 'imperfect' and not happy with their own identity.”
>
> Individual, Student

There is also a suggestion in a few comments that tensions may evolve between the child and mother, since the mother has mitochondrial disease and the child does not.

Several respondents consider the trade-off between the parents’ feelings and happiness and those of the child, sometimes arguing that parents are compromising the well-being of a child by allowing it to be conceived through mitochondria replacement. They believe that the complications around identity are a heavy burden to be imposed on a child.

> “Whatever the unknown psychological or physical burdens that resulted, however, it has to be underlined that these would be borne not by the parents, but by the offspring.”
>
> Organisation, Comment on Reproductive Ethics [CoRE]

Respondents suggest a variety of other aspects that could disturb or confuse the relationship between the child and their family. Examples are that the child may be curious about 'siblings' it has through its mitochondria donor, and that any family difficulties or behavioural problems could be regarded as a consequence of the child's genetic relationship to its mitochondria donor.

> “Despite the fact that it appears there will be no significant inherited characteristics from the procedure there may always be some doubt, particularly of relationships within the family become strained for any reason. The mitochondrial donation could then be blamed, albeit with little foundation.”
>
> Individual, Other

In a similar vein, several respondents emphasise that it is likely that the child will have a desire to know its mitochondria donor. Discussions about whether or not this should be possible are covered in chapters 7 and 8; here we focus on the possible impact of the donor's existence on the child's well-being. Respondents to question 3 suggest that children may consider their 'third' parent to be missing from the environment they grow up in. Some offer comparisons with children who were adopted or the product of gamete donation and assert that these children are known to develop a wish to find out about their biological or genetic parents.

> “If a child gets DNA from 3 or more parents this will lead to desires to want to know the identity of the donor parent. Reasons could vary from thankfulness, curiosity, identity confusion, or desperate need to be loved.”
>
> Individual, Other

A few respondents describe potentially problematic aspects of the presence of a mitochondria donor. One respondent states that donor-conceived individuals are increasingly seeking psychological support, suggesting that this may also be the case for children born with the help of mitochondria replacement. Another believes that if the child's family is not a pleasant one to grow up in, the child may wonder about the family environment their mitochondria donor might offer.

Among many argued cases stating that there will be emotional or psychological consequences for the child, or that there will not, there are a few responses emphasising that the proposed techniques are fundamentally different from what we have knowledge about, and that as a consequence it is not possible to predict how resulting individuals will feel about them. Some respondents highlight the experimental nature of the techniques and the need to consider the long-

term psychological effects for individuals conceived in this way, as they may only encounter identity issues later in life. A few suggest that the potential implications on individuals' sense of identity are likely to decrease if mitochondria replacement would become more common.

> "Yes, it is inevitable that the knowledge that they owe their genetic origins to three persons will affect those concerned, in ways that cannot now be predicted, since their situation would be entirely unprecedented."
>
> Individual, Other

The impact of society's response to children conceived with the help of mitochondria replacement is mentioned in several responses to question 3. Some respondents who perceive the mitochondria donor as a 'third parent' worry that children may feel that they do not meet the norm of having two parents and that this could confuse them. Others highlight the risk of negative reactions children may be subject to from people who suffer from mitochondrial disease, or from people with strong views on reproductive ethics or genetic modification.

> "Given that many people refuse to eat genetically engineered foods, how does one tell one's friends, family, potential mate that you are genetically engineered?"
>
> Organisation, International Center for Technology Assessment

Another strand of argument broached in a small number of responses is around how public opinions are shaped. Respondents emphasise the risk that children conceived with the help of mitochondria replacement will carry a label that identifies them as a 'three-parent baby' or a 'GM baby' and that this may have a detrimental impact on their well-being. A few respondents specify the role of media in influencing public attitudes, and express concern that this may make children's lives more difficult."

> "They fail to reckon with the power of our media which have already represented these techniques as creating 3-parent or 4-parent children. As these concepts are being increasingly embedded in the public consciousness, it will be virtually impossible to uproot them."
>
> Individual, Other

Some respondents make other comments about the implications for wider society. A few discuss the legal status of the mitochondria donor, sometimes stating their belief this is important to consider in the light of kinship and identity. A few others posit a concern about the pressure that intending parents may feel when they would need to decide about the option of mitochondria replacement.

> "[…] prospective parents who fear passing on the disease could ultimately be labelled irresponsible if they don't have the treatment, but, at the same time, they could sacrifice bonding with their child if they go ahead."
>
> Individual, Other

Many comments include considerations about the current state of society and interpersonal relationships within it, in some cases to support a view that society will be ready to accept individuals conceived through mitochondria replacement, in other cases deploring that the techniques will further erode traditional structures.

> "The multiple parent issue may become a catalist [sic] to a very dangerious [sic] society change. We are confused enough already, and social studies have backed this up."
>
> Individual, Other

6.2.4 Comparing with other procedures

In considering the potential implications on children's sense of identity, many respondents propose comparisons with other procedures. There are great variations not only between the procedures that respondents liken to mitochondria replacement, but also between the conclusions they draw from this. The following set of quotations captures this very aptly: two respondents each citing both adoption and gamete donation, one as a satisfactory argument that identity implications will be manageable; the other to highlight additional complications specific to mitochondria replacement:

> "There are many happy people raised with adoptive parents, surrogate mothers, or sperm-donor fathers; these don't have any bearing on the child's wellbeing."
>
> Individual, Other

> "A person who is adopted or born from the result of donor sperm or eggs might find themselves asking where they come from. At least in these situations the question has a definable answer."
>
> Individual, Other

The most commonly cited procedure respondents to question 3 compare mitochondria replacement with is gamete donation. In most of these responses the comparison leads respondents to argue that the potential implications on a person's sense of identity are socially and ethically acceptable, sometimes highlighting that society already accepts the consequences of gamete donation. Many respondents feel that the impact of mitochondria replacement can be viewed as equal to that associated with gamete donation, while several others suggest that the proposed techniques will impact less, as no nuclear DNA is involved.

> "We therefore consider that mitochondrial transfer techniques are likely to raise far fewer social and ethical issues surrounding offspring identity than are already raised by existing fertility techniques that are widely accepted, such as gamete donation and surrogacy."
>
> Organisation, Wellcome Trust

A number of respondents are concerned about the implications of gamete donation on children's sense of identity, and emphasise that their concern extends to mitochondria replacement. Some cite publications containing examples of donor-conceived individuals struggling with identity questions.

> "We do however have increasing anecdotal evidence about the importance of genetic heritage and parental bonds for those born from donated gametes and their desire to know about their full genetic heritage (3). Some have described anger at feeling like a medical experiment and cited problems with understanding identity for themselves and their own children" (4)"
>
> Organisation, Christian Medical Fellowship

There are numerous comments considering a comparison of the implications of mitochondria replacement on an individual's sense of identity to those of organ, blood, or bone marrow transplantations. Several of these comments are from friends or relatives of people affected by mitochondrial disease. Most of the respondents drawing such comparisons do so to underline their argument that implications will be minor.

> "A person can have an entire organ transplanted (heart, lung, liver, kidney, etc...) and not suffer any change to their indentity [sic]. Indeed, transplants introduce foreign DNA into the recipient. I do not see this as being any different from using a donor's mitochondrial DNA"
>
> Individual, Other

A small number of respondents specifically disagree with the suggestion that in this context mitochondria replacement can be compared to blood or bone marrow transplantations.

> "The SCHB is of the opinion that the donation of an unfertilised or fertilised eggs can certainly not be thought similar to a bone marrow or blood donor. Biological elements partaking in the creation of life are completely different to biological elements that are used in the treatment of an already existing life."
>
> Organisation, Scottish Council on Human Bioethics

Another procedure often referred to in responses to question 3 is adoption. The pattern of these responses is very similar to that referring to gamete donation, with a split of opinion between (more) respondents who believe both procedures have acceptable implications on identity and (fewer) respondents who think both procedures cause identity-related harm.

Some 130 respondents feel that the implications of the proposed techniques on an individual's sense of identity will be equal to other, existing procedures. While 15 respondents assert that the implications of mitochondria replacement will be greater, often identifying the mitochondria donor as the complicating factor; 42 respondents believe that there will be fewer implications, generally referring to the perceived insignificance of mitochondrial DNA. The latter group includes a number of respondents who identify themselves as friends or relatives of a person affected by mitochondrial disease and a few who indicate that they have personal experience of gamete donation.

> "As an adoption worker myself I am very aware of the issues of identity and the impact on individuals of not knowing where they came from genetically. I spend much of my working life helping adopted adults find information and trace birth relatives. However, I believe this would be far less of an issue to a person born by the technique proposed and the relief from the anxiety for female children of passing on the disease to their children would be immense."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

The next chapter, chapter 7, discusses respondents' views on other procedures in more detail.

Chapter 7 Question 4a: the status of the mitochondria donor

7.1 Headline findings

987 respondents answered question 4a, which asked:

> **In your view how does the donation of mitochondria compare to existing types of donation? Please specify what you think this means for the status of a mitochondria donor.**

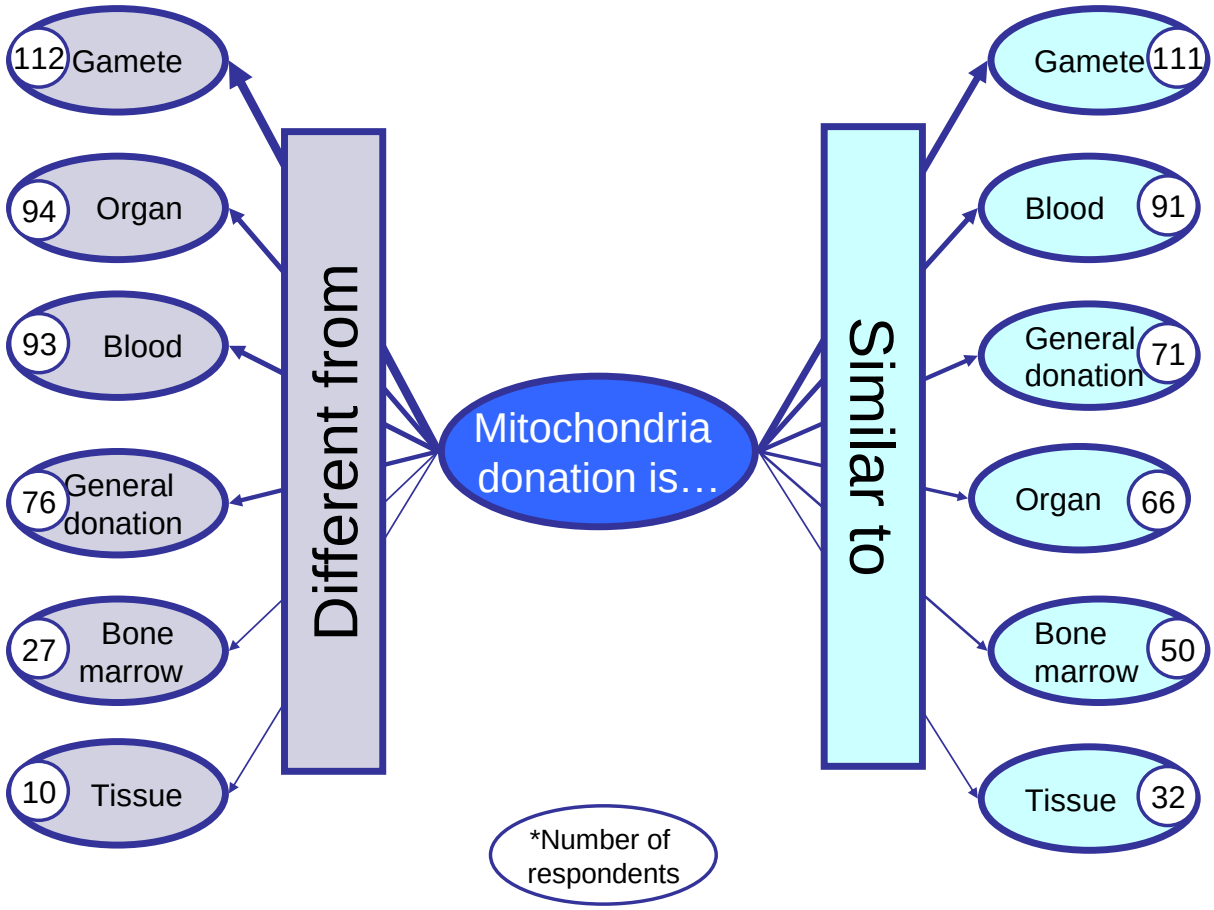
Responses to question 4a included a wide variety of views as to whether mitochondrial donation could be compared to existing types of donation, or represented an entirely different proposition. Typically respondents who believed the significance of mitochondrial donation to be similar to other non-reproductive donations supported its introduction, while those who regarded it as equivalent to donating sperm or eggs where more cautious.

7.2 Summary of comments

7.2.1 Comparing mitochondrial donation

The majority of respondents to question 4a suggest existing types of donation, with which to compare donation for mitochondria replacement and the most common are depicted in the diagram below. As the diagram shows, for most comparisons as many respondents thought mitochondrial donation was similar, as thought it was different to another type of donation. As the narrative below describes however, many different explanations were given for these comparisons, and often two respondents would conclude the same thing for entirely different reasons.

Figure 6 Comparative views on mitochondria donation in responses to question 4a



As shown above, there are a number of respondents who suggest that mitochondria donation is similar, in general, to other kinds of donation without specifying further. These respondents were typically supportive of the techniques being introduced into clinical practice, often citing the perceived benefits of this for health:

> "It is very similar. A donor would be increasing the chases [sic] of a more healthy, longer life for an individual. The organ being donated makes no difference."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

Similar sentiments however are expressed by some respondents who feel that mitochondria donation is totally different from other types of donation in a positive way:

> "I think that mitochondrial donation is in a different category from other types and that the emphasis should be on its potentially remarkable role as a contribution to preventive medicine."
>
> Individual, Other

A more common view among those arguing that mitochondrial donation is fundamentally different is that this difference warrants caution about introducing it to practice; either because it introduces new phenomena such as the genetic contribution of three parties, or because they believe it is unethical. These arguments are explored in more detail in the following sections. Others highlight that the donation differs fundamentally from other (non-reproductive) donations as the impacts persist through the germline rather than affecting one individual only.

Among respondents who indicate that they have personal experience of gamete donation or donor conception there is a divergence in views similar to respondents overall. While six respondents from this category state that they see mitochondria donation as different from gamete donation, five say they think it is similar. Within this category, several respondents suggest that mitochondria donation is similar to organ, blood or tissue donation, while very few emphasise a difference.

Comparing with gamete donation

The most common comparison made by respondents in question 4a is between mitochondrial donation and the donation of gametes (eggs or sperm), with equal numbers arguing that the two types of donation are similar as argue that they are different. Organisations suggesting similarity include PROGAR and the National Gamete Donation Trust; organisations suggesting difference include the Wellcome Trust and the Nuffield Council on Bioethics as well as the Anscombe Bioethics Centre. Among those who believe that donating mitochondria is similar to donating gametes, some argue that the transfer of genetic material is the deciding factor, which differentiates these procedures from blood or organ donation. A few note that the proportion of genetic material contributed is much smaller than in full gamete donation, but still feel that it is significant.

> "It is the same irrespective of the quantum & type of DNA donated. Hence, the status of the donor should be the same as with donated eggs or sperm."
>
> Individual, Other

For other respondents the key point is whether mitochondria affects identity; where respondents believe that there is no effect on traits or characteristics they suggest the donation can be seen as similar to blood donation, for example, but would be substantively different if such an effect did occur. There are some respondents who state their belief that mitochondrial DNA does not affect identity traits, often likening it to a 'functional' structure such as bone marrow. In contrast a few respondents suggest either that the role of mitochondria in identity may be discovered as the science of genetics evolves, or that it does contribute in some sense already, for example:

> "The donation of mitochondrial DNA is very personal and individual reflecting a donation of an individual's personal characteristics even if this means how they function biochemically rather than their outward bodily characteristics."
>
> Individual, Other

An alternate focus for some respondents is the procedure for the donor, which they see as similar to that for egg donation. Some of these respondents suggest this comparison as evidence for the acceptability of the introduction of the techniques (i.e. it's no different than an already widely accepted process). However others express concerns about the existing process which they believe apply equally with the proposed techniques:

> "The donation of mitochondria is going to involve egg donation. There are already more eggs wanted than donors ready to provide them. Egg donation is an unpleasant and risky business. It is in no way comparable with easy blood donation."
>
> Individual, Other

A third line of reasoning for the similarity between mitochondria and gamete donation for some respondents is that the donor in both cases is in some sense a 'parent' of the resulting child, either in a biological sense, or for a few respondents, in the sense of having a moral responsibility towards the child (explored more in section 7.2.2 below).

Respondents who state that mitochondria donation is different to donating gametes commonly suggest that the two are different because no nuclear DNA is transferred. Some specifically mention characteristics, arguing that because the donation will not impact on the child in this sense, the mitochondrial donor is not equivalent to an egg or sperm donor. Respondents arguing along these lines tend to support the introduction of the techniques, and feel that the donation of mitochondria is 'less' consequential than classic gamete donation.

In contrast several respondents who oppose the introduction of the techniques also argue that mitochondrial donation differs from egg donation because the procedure results in changes to the donated egg, altering the relationship between donor and child. Some of these respondents describe this change as affecting the extent to which the donor is the 'mother' of the child:

> "The spindle is not an egg and without an egg there is no embryo. The egg donor is a kind of partial mother, just as the spindle donor is a kind of partial mother.
>
> In the case of PNT the egg donor is not the mother directly of the final embryo created, but of an embryo who is destroyed to create that final embryo."
>
> Organisation, LIFE Charity

Others argue that potential donors may not understand this apparent difference to typical egg donation, and that this lack of information would make them less informed and able to consent.

Comparing with embryo donation

There are a number of respondents who make a specific comparison between donation for mitochondria replacement and the donation of embryos to research in which they may be destroyed and express ethical concerns about this process (153). The ethical argument made is that the donation of viable eggs which are used to create embryos which are not intended to be born results in the destruction or death of that embryo. Some respondents refer specifically to PNT, arguing that it amounts to the destruction of an embryo in order to create another, while others do not specify one or other of the techniques, and some specifically mention the donation of eggs rather than embryos. In addition to ethical concerns, some of these respondents suggest that the donor in such a situation may experience guilt or remorse after the donation:

> "A mitochondrial donor is someone who is substantially risking her health and future fertility if she donates eggs: if she donates embryos, she is delivering her offspring up for destruction. A woman is in the position of one who is giving her embryos up for the purposes of research which is of no benefit to the embryo, and results in its eventual destruction. This is to ask women who donate embryos to treat their offspring as if they were commodities: which might be damaging to her relationship with subsequent or existing children (if one child is a commodity, why not all of them?)"
>
> Individual, Other

Alongside concerns about the 'destructive' use of embryos and eggs in the techniques, often raised alongside concerns about the effect on the donor. Many of these respondents mention the procedures involved in donating eggs, particularly artificial stimulation. Others suggest that exploitation can occur when donors are offered financial reimbursement or access to fertility treatment in exchange - respondents typically note that these concerns exist for all techniques involving egg donation, but suggest they could be exacerbated by the introduction of the techniques into clinical practice. Others raise particular concerns about the availability of donors, either because they believe women will be less likely to donate given the perception of the techniques described above, or because of a general shortage of egg donors.

Comparing with organ, tissue and blood donation

Although many respondents, including the Association of Clinical Embryologists (ACE) Executive Committee and the British Medical Association, specifically mention blood, organ or tissue donation they typically use the same arguments. Those who believe mitochondrial donation is different to these types of donation often refer to the genetic component of mitochondria, as described above. Others note that mitochondria replacement alters the germline, and thus the donation cannot be viewed in the same light as donations such as organs which affect only the individual involved. A small number of respondents argue that difference is based on the donor; they argue that the mitochondria are effectively donated by the egg or embryo (which they view as a separate person), rather than by the mother, and as such no informed consent is given. Others suggest that there are negative consequences of mitochondrial donation for the embryo or egg donated, where tissue donation has no significant effect on the donor:

> "I think there is an enormous difference between donations that save lives (such as blood donation) and donations that result in the loss of (embryonic) life, such as egg or mitochondria donation."
>
> Individual, Other

Those who argue that blood, organ or tissue donation is similar to mitochondrial donation typically argue that there is no nuclear genetic contribution, and thus no impact on characteristics, as described above.

Comparisons: variations

Some respondents specifically address differences they see in the status of donors to each technique. Of these most raise the arguments described above regarding the use of embryos in PNT, but tend still to oppose both techniques. A few respondents discuss their view that donation for MST is equivalent to blood or organ donation, as there is no genetic contribution, or to a sperm donation, in that it is likely to be accepted in a similar way.

There are two respondents who mention the sex of the resulting child - noting that as mitochondria are passed on only via the female line, the germline change is only passed on via female children. One suggests that this effectively makes a mitochondrial donation which results in a female child similar to gamete donation, but a donation resulting in a male child is more like an organ donation, where no change persists beyond the individual.

7.2.2 The mitochondrial donor

Status of the donor

Views on the status of the mitochondrial donor are strongly correlated with views on the status of the donation in relation to other types of donation; this section focuses specifically on the donor as an individual, with many arguments summarised above. The most common points raised by respondents in relation to the donor concern whether they are a 'parent' to a child conceived via the proposed techniques - with slightly more respondents supporting than opposing this concept. In responses from respondents who indicate that they have personal experience of gamete donation or donor conception few comments are made about the donor status. Three of these respondents suggest the donor is a parent to the child, one respondent states the donor is not, and two respondents say the donor has no rights or responsibilities towards the child.

> “We find no distinction. s.47 of the Human Fertilisation and Embryology Act 2008 states: 'A woman is not to be treated as the parent of a child whom she is not carrying and has not carried'. The Humanist Society Scotland does not believe that the donor of mitrochondria [sic] can have the same status as a reproductive egg or embryo donor, nor that mitrochondrial [sic] donors should be legally pressured to be identified to the adults born from the donation.”
>
> Organisation, Humanist Society Scotland

Those who believe that the mitochondria donor is in some sense a ‘parent’ to the resulting child tend to focus either on the genetic contribution of the donor, arguing that the fact that their DNA is passed on qualifies them as a ‘parent’. Others refer to the essential role of the donor in the conception of the child.

> “The person could not exist without this mitochondrial DNA and therefore I feel this makes the mitochondria donor a parent of the child in a very real sense as they have been integral to the process of conception.”
>
> Individual, Other

Many of those who state their belief that the donor is a ‘parent’ qualify this, suggesting that the role is shared with the intended parents (who contribute their nuclear DNA) - a smaller number state specifically that all three genetic contributors have an equal role as parents.

Despite the number of respondents who argue that the donor has a role as a parent, far fewer suggest that they have particular rights or responsibilities towards the child - which may be because many of those who believe the donor is a parent do not believe the techniques should be permitted. Statements about responsibilities of the donor tend to identify that these responsibilities exist without going into detail about what they entail.

> “I think that the mitochondria [sic] donor is a third parent. I think that any techniques which use genetic material from three people has this problem.”
>
> Individual, Other

In contrast those who argue that the mitochondrial donor should not be considered a parent often suggest that the genetic contribution is not significant enough, or is purely functional, and so does not bestow a parental relationship. Others focus on the social role of parenting, arguing that the donor contributes genetically, but has no role raising the child, and as such is not a parent.

Those who do not believe there should be a parental relationship between donor and child also tend to believe that the donor should not have rights or responsibilities over the child, with several returning to comparisons with other donation scenarios:

> “Mitochondrial donation is more akin to giving blood than it is to surrogate parentage. The Mitochondrial donor and child should not have any contact with the child and has no rights over the child's upbringing.”
>
> Individual: Student

A number of respondents (24) specifically mention the legal status of the donor, with the majority arguing that there should be no binding legal requirement on the donor with regards to contact or obligation towards the child. This is seen as a potentially challenging issue by some, who suggest that the complexities of the relationship between intended parents, donor and child may result in legal challenge, or cumbersome legislation. The theme of confusion is echoed by others, who

express the view that the status of the donor in general is unclear, with some suggesting that this is symptomatic of overall problems with the techniques.

> "We simply cannot predict the meaning that the mitochondrial donor (and the donation itself) will have to those directly affected – and neither is that meaning likely to be (i) static over their lifetimes or (ii) standard either within or across the different 'groups' concerned."
>
> Organisation, PROGAR

Many respondents make comments in question 4a on the extent to which information should be available to a child conceived as a result of the techniques; these arguments are explored in the following chapter. However a number of respondents express more generally their view that the donor should have the right to anonymity, either as a blanket policy or as an option they could choose. Concerns for the right of the donor to anonymity are often associated with the view that the donation is an altruistic act, which should not have harmful implications for the donor. Many of these respondents associate the act of mitochondrial donation with 'helping' a child, rather than 'creating' one:

> "In the same way that organ, egg and sperm donors consent to helping another life, a mitochondrial donor would be doing the same-not wanting a child etc but wanting to help another human being "
>
> Individual, Personally affected by mitochondrial disease

However there are some respondents who take the opposing view, and feel that something about the nature of mitochondrial donation, either its genetic aspect, or the fact that life is 'created' as a result, is a significant enough contribution to the resulting child that they must have the right to information about the donor.

Chapter 8 Question 4b: the status of the mitochondria donor

8.1 Headline findings

A total of 1,039 respondents answered question 4b, which asks:

> **Q4: b) Thinking about your response to 4a, what information about the mitochondria donor do you think a child should have? (Choose one response only)**
>
> **1) The child should get no information**
>
> **2) The child should be able to get medical and personal information about the mitochondria donor, but never know their identity**
>
> **3) The child should be able to get medical and personal information about the mitochondria donor and be able to contact them once the child reaches the age of 18**
>
> **4) Other**
>
> **5) I do not think mitochondria replacement should be permitted in treatment at all.**
>
> **Please explain your choice.**

As summarised in the figure 7 below, the largest number of respondents chose option 5, implying that the other options are not relevant to them as they would rather not see the techniques permitted. Looking at the different respondent types, the only group where a majority selected option 5 are respondents describing themselves as 'other' (see chapter 2). Among specified respondent types (e.g. patients, relatives, students) the opinion is divided between all five options.

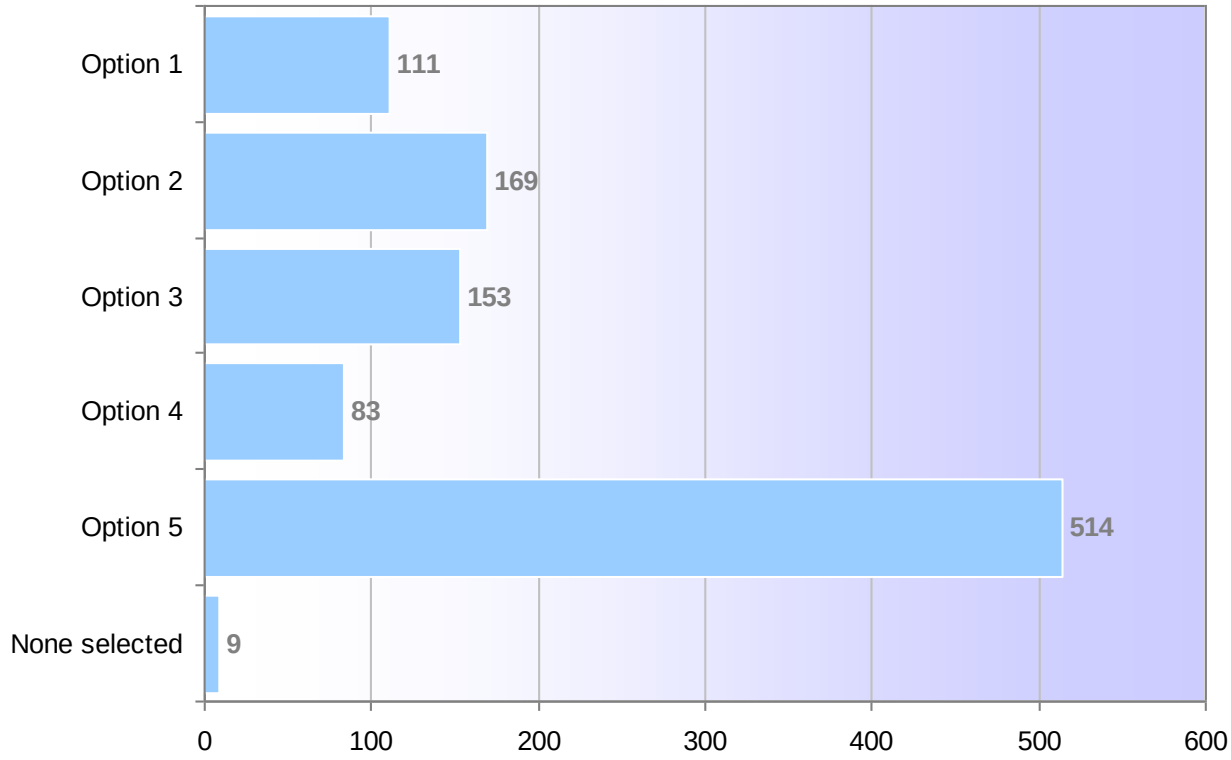
Respondents' choices divided fairly evenly between options 1, 2 and 3, with option 1 receiving the fewest selections and option 2 the most among them. A smaller number of respondents selected option 4, 'other', and suggest different approaches or variations to what is proposed in options 1, 2 and 3.

Though most respondents selected one of the 5 options presented, nine respondents made further comments without selecting any of the options presented.

Looking at the options selected by different types of respondents, there is a relatively clear preference for option 2 among those who indicate they are personally affected by mitochondrial disease and/or a friend or relative of someone affected by mitochondrial disease. Among the (few) respondents who indicate that they have personal experience of gamete donation or donor conception, options 2, 3 and 4 are selected more often than option 1. Very few respondents from the categories mentioned here have selected option 5.

Among stakeholder organisations options 1 and 3 are more often selected than option 2. Proponents of option 1 include the British Medical Association and the Nuffield Council on Bioethics; option 3 is supported by the Church of England (Mission and Public Affairs Council) and PROGAR, among others. Human Genetics Alert, the Church of Scotland as well as some other organisations state a preference for option 5.

Figure 7 Preferred option in responses to question 4b

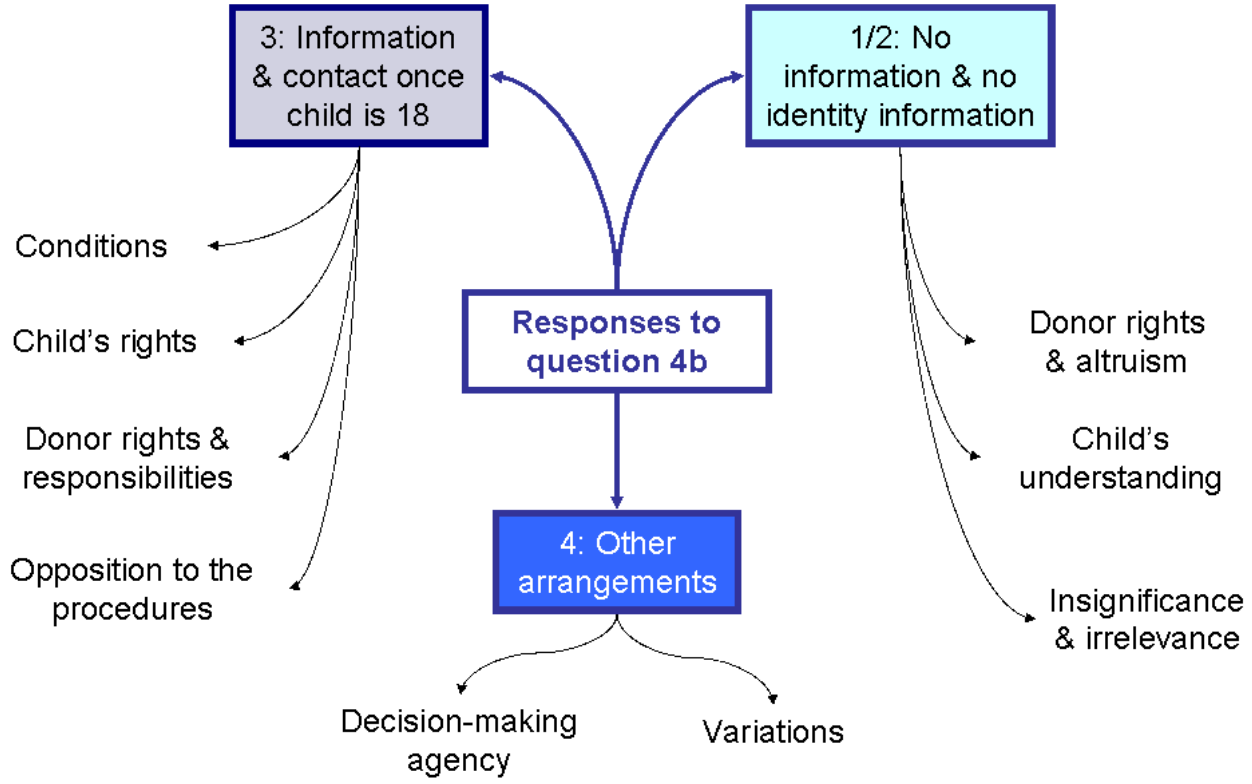


Respondents selecting options 1 and 2 express some similar views in explanation of their perspectives, frequently focusing on the ethical status of the donation and the rights and responsibilities thought to be contingent. A few choosing option 1 state explicitly that option 2 would be their next preference, and vice versa. Similarly, the explanations of respondents selecting options 2 and 3 display some similarities, often anticipating future medical needs and identifying concerns of offspring of the techniques.

Respondents who comment that they oppose the techniques generally selected option 5, although a smaller number selected option 3, in order to express their preference about disclosure of information in the event that the techniques are to be permitted. Their views are explored further in the section on option 3, below.

This chapter examines in turn the explanations of respondents, grouped according to the options they preferred for donor information disclosure. Their explanations are explored in more detail below under the following sub-headings:

Figure 8 Responses to question 4b



8.2 Summary of comments

8.2.1 Option 1 (no information) & option 2 (some information but not identity)

Respondents selecting options 1 or 2 agree that the identity of a donor involved in the techniques should at no point be disclosed to the child, although those who chose option 2 think that medical or personal information should be available to them. Explaining their choices, these respondents raise many similar considerations. Further, three respondents selecting option 1 said option 2 would be their second choice, and three selecting option 2 said option 1 would be their alternative preference.

Insignificance and irrelevance

A number of respondents selecting options 1 or 2, including several who are personally affected by mitochondrial disease, or a patient/relative of someone who is, argue that no more information should be disclosed on the grounds that the donation has the same status as a blood or organ donation. They say that as those donations guarantee anonymity, so should the donation involved in these techniques. A smaller number of respondents selecting either option compare the donation to that of eggs or sperm, arguing that its lesser significance for the genetic identity of the child indicates that less donor information should need to be disclosed. A few make similar arguments based on comparison with adoption or surrogacy. A few respondents selecting option 2 suggest the procedure is similar to egg or sperm donation, but suggest disclosing the donor's identity is complicated, or should be conditional on consent.

> "The reason children born following donor conception require information about the donor is because the information relates to them, as a person, and the donor's genes have

> contributed to their physical appearance and personal characteristics. The same does not apply to donated mitochondrial DNA. The closest analogy is to blood or bone-marrow donation which is carried out anonymously with the recipient receiving no information about the donor."
>
> Organisation, British Medical Association

Some respondents who refute the need to disclose the donor's identity based on the comparative status of the donation go on to explain that their views are informed by the function of mitochondrial DNA. They say that as mtDNA does not determine the identity or the traits of the child, the donor's identity can have no significance. Others say they can't see circumstances in which it would be necessary or important for the child to access more information about the donor.

> "I believe that children conceived by this technique should not need any information on the identity of the mitochondrial donor. As the conceived child will not inherit any personal characteristics or traits from the mitochondrial donor, they will have no legitimate interest in their identity."
>
> Individual, Member of staff at a licensed HFEA centre, Researcher

Some respondents selecting either option 1 or 2 explain their view that certain circumstances might influence what donor information should be disclosed. A small number of respondents selecting option 1 comment that in case of new medical evidence or other unforeseen developments, the relevant information should be confidentially stored, or the rules about its disclosure might need to be reconsidered. Comment on the circumstances of disclosure is significantly more common among respondents selecting option 2, some of whom mention the possibility of medical developments that might justify more information. Most frequently, they describe these circumstances as likely to be connected to the health of the child, other medical developments in the field, or unforeseen consequences of the techniques.

Child's understanding

Respondents sometimes link the way children are informed about the techniques to the significance of information about the donor. Some say they believe children should be given no or limited donor information, but do have a right to understand the process that has taken place. Others state concern that making available too much information about the donor could lead the child to an inaccurate understanding of its medical or personal significance to them.

A small number of respondents reflect on the motivation of the child in seeking information about their donor. Some of the respondents favouring option 1 note that a child's curiosity would be understandable, but that it need not require the disclosure of more information than is fitting for the donor. This view is connected to their feeling that the significance of the mtDNA is limited, and it is vital that children understand this.

> "…The child should have the right to know how they were conceived and why, but have it explained that their genetic characteristics such as physical traits, personality traits, intelligence etc come from the parents they are growing up with. I think it would confuse the issue if they were to have the right to know who the donor was given the minimal input from the donor mitochondria to the person's make-up."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

Donor rights and altruism

Other views common to respondents selecting options 1 or 2 focus on the rights of the donor, or considerations about the experience of donating and about privacy. Some express concerns about

the possibility of intrusion into the donor's life if their identity were to be disclosed. Others note that knowing a child might seek them out later in life would be a disincentive to donate, or note that guaranteeing donor anonymity would likely encourage altruistic donors. Some describe the relationship between the donor and the parents as altruistic or as offering a simple medical 'repair', and so part of a dispassionate and impersonal act of generosity that need not imply future contact or association.

> "I feel that using a mitochondria donor would be a gift. A way to erase the spelling mistake within my gene pool. My child would be made up of myself & my partner & very little of the donor. I think having access to medical conditions & personal information would feed any interest but that person isn't the main gene donor & I feel there's enough reassurance there for a child as its still made up of mum& dad genetically with some help from a kind person..."
>
> Individual, Personally affected by mitochondrial disease

Comments specific to option 2

Though most comments made by respondents favouring either option 1 or option 2 are similar, some comments made by respondents selecting option 2 weren't reflected in comments of those who chose option 1.

Specifically, nine respondents select option 2 and mention specific reasons why personal information should be made available to the child. In most cases respondents say this disclosure should be subject to the relevance or utility of personal information, although one respondent suggests any criminal history of the donor should be available to the child.

> "In case of any medical complications in the child, the knowledge of the medical and personal information could be useful to reduce the certain complication. However the donor identity may be unknown as only a small percentage of the donor is a part of the child."
>
> Individual, Student

Four respondents selecting option 2 say that option 3 would be their second choice, usually suggesting that the two differ little, and that the donor's consent for the disclosure of their identity should be the critical factor.

8.2.2 Option 3 (information and ability to contact once child is 18)

Respondents selecting option 3 tend to attach greater significance to the results of the technique for the child, and often consider these outcomes at length in their explanations.

A number of these respondents echo explanations given by respondents selecting other options on information disclosure. For instance, some respondents state relatively straightforwardly that they regard option 3 as the appropriate arrangement since they see mitochondria replacement as equivalent to egg or sperm donation.

Child's rights

Of respondents choosing option 3, several explain that they feel it is the child's right to know the identity of the donor. Many of these accept the curiosity or the emotional or medical needs of the child, and a number give their explanations in terms of parenthood or origins, connecting the disclosure of the donor's identity with the child's ability to understand their own background. Some respondents who select option 3 cite the child's general right to information about their biological make-up, and others mention that they may wish to thank the donor.

Eight respondents frame the child's rights differently, focusing on the right to understand the process that took place. For most of these respondents this is the responsibility of the child's parents, and they anticipate that if done properly, there would be no need to withhold any information from the child, who may be content not to act on any information they could access.

For nine respondents, the decision on how important knowledge of the donor's identity is must rest with the child. For this reason, they consider option 3 the best arrangement, so that the information should be available when needed.

> "Paternalistic and/or culturally discriminatory assumptions about whether or not such offspring will need information to meet their identity (or future medical) needs have no place in the modern world and we should not be risking the future well-being of those offspring for whom it may prove important…"
>
> Organisation, PROGAR

A number of respondents selecting option 3 state in their explanations their support for the provision for disclosure of information when the child reaches adulthood or the age of 18. Some respondents reaffirm this age conditionality, but six suggest that the disclosure might be appropriate or helpful earlier in the child's life, or simply that the age limit ought to be fixed elsewhere.

Donor rights and responsibilities

A smaller number of respondents stress that the child's rights must be balanced against the rights of the donor. Though only four respondents who select this option state that disclosure of the donor's identity should be subject to their explicit consent, a number of other respondents draw attention to the rights of the donor to decline to enter into a relationship with the child, for instance, or to maintain their distance from the child.

> "This option seems to provide the maximum freedom to obtain information if the child wishes it on reaching adulthood, without infringing the donor's right to anonymity."
>
> Individual, Other

Eight respondents who select option 3 explain their view that it would be justified to disclose the information and identity of the donor because they regard it as part of the donor's responsibility. Specifically, they suggest the donor should take account of the possibility of future contact before the donation takes place.

Other option 3 respondents, though, feel greater flexibility would be appropriate. Some suggest that the disclosure of donor identities should be flexible to a degree, dependent of the will of some combination of the parties, or else different case-by-case depending on the needs of the child. A few respondents selecting option 3 suggest that disclosing the identity of the donor would be less problematic if the donor were likely to be someone known to the family benefitting.

Conditionality

Many respondents who select option 3 impose conditions on the disclosure of information outlined. A few respondents specify that the rules on donor identity should reflect the technique used: so, a child born using MST should have the right to know the identity of the egg donor, while one born by PNT should know the identities of both the egg and sperm donors involved in the process. Another suggests that since male children will not pass on the donor mitochondria, they need only receive the information implied in option 2, while female children should know the donor's identity too, as in option 3. Others refer to the significance of this transmission through a female child, without asserting the possibility of different rules.

Some respondents selecting option 3 suggest further medical evidence or outcomes as conditions on the disclosure of donor information. Similar to arguments made by respondents selecting option 2, these respondents consider the possibility that information about the donor might be important in future medical research or treatment. A couple suggest that if the techniques were shown to transmit some characteristics to the child, the donor's identity would be important to disclose.

> "…as the replacement of mitochondria is a new technique without the benefit of years of results it is possible that unforseen [sic] problems may arise. I would therefore be in favour of allowing the child to obtain medical and personal information that may help in this case. That said, this should in no way lead to the situation where a mitochondrial donor could be found responsible for the future health and well-being of the child."
>
> Individual, Family member/friend of someone affected by mitochondrial disease, Other

Opposition to the procedures

Although most respondents opposed to the techniques select option 5 as their preferred model for managing donor information, seven select option 3, and go on to explain their choice. Most explain that they would prefer it if the techniques were not permitted, but in the event that they are, that option 3 would be appropriate because of the biological significance of the procedure for the child.

8.2.3 Option 4

Respondents who selected option 4, signifying some other arrangement for disclosure of information, sometimes propose a specific variation on options 1 to 3. Their focus also tends to be on a more flexible approach, depending on circumstance and often based on mutual agreement between the parties involved. A few respondents, for instance, again suggest the need for different arrangements according to whether MST or PNT is used, or depending on future understanding of the functions of mtDNA or the medical consequences for the child.

> "This one-off tick box does not allow those opposed to these techniques to say how to accurately consider the implications of these techniques. If MST is legalised, such children should not be deprived of knowing their egg donor mother.
>
> If PNT is legalised, such children should be fully informed of the procedure and have full knowledge of the woman who donated the second egg and the man whose sperm was used to create the donor embryo with that second egg."
>
> Individual, Other

Decision-making agency

While some of these respondents repeat the view found above that the decision on disclosure of their identity should rest with the donor, a number of others suggest that the donor should enjoy some discretion in what other information is shared with the child, or even, in one instance, that the decision should be reversible. A few respondents note the possibility that discretion might encourage more donors to come forward.

A few other respondents suggest that the parents should have greatest agency in decisions about what information is shared with the child. One suggests the need for input from medical professionals too, while others say the parents should hold on to the information until the child is better able to understand it.

A number of respondents repeat views described above that attribute a responsibility to the parents for ensuring the child's appropriate understanding of the procedure and whatever information is disclosed to them, and when. In a variation on this perspective, three respondents

believe that protecting or ensuring the welfare and independence of the child is paramount in considering the disclosure of information.

For many respondents, though, the decision on disclosure of information to the child must be shared. Some say it should be negotiated according the wishes of the child and the donor, while others suggest that the donor and the parents should be the key agents. As seen above, many more respondents than these hint at these possibilities of joint responsibility in describing varied conditions and circumstances of consent and disclosure.

> "It should be the choice of each donor as to what information is provided, along with any other conditions of their donation, and the choice of the parents as to whether to accept these conditions. There is no need for blanket conditions; donors can be matched up with compatible parents."
>
> Individual, Other

Variations

Some respondents defer in their explanations to established rules governing the disclosure of information in other donation procedures. A few say it should be the same as for organ, blood or bone marrow donation, while one identifies egg or sperm donation as the appropriate model.

A number of respondents selecting option 4 describe an alternative variation on options 1 to 3. A few respondents suggest that only medical information should be disclosed. One respondent argues that as well sharing medical information from birth, personal information about the donor - falling short of identification - could be positive if disclosed once the child reaches 18. A small number of respondents support option 3, but disagree that it should be age-limited. A few others stress that the information shared need only be minimal. A number also distinguish between MST and PNT in exploring these variations.

> "That the status of mt donors depends on whether MST or PNT transfer has been undertaken
>
> (a) With MST, the mt donor is in a similar position to a blood donor. If an individual needed blood to save their life and then subsequently went on to conceive a child, it could be said that the child born was as a result of the life-saving blood donation. But the donation is not an integral part of the child's identity. In the case of MST, the healthy egg has been deliberately extracted for this purpose with the donor knowing it would be used in this way without her nuclear DNA, but with the tiny amount of mt DNA being preserved in a future life…
>
> (b) With PNT, it is felt that the donor's identity is stronger (despite it still only being the same tiny amount of mtDNA that is preserved), because of the deliberate creation of the embryo rather than the donation of an egg, perhaps in a similar way to those who have received heart or face transplants where the recipient may question identity. Here there is a donor embryo made up of two peoples DNA and whilst the mt is only connected to the maternal line, this healthy mt from the donor embryo is only available because DNA from two people has come together to make the embryo. If we're thinking in a social context, it is possible that the donor conceived person might also want to know the fourth 'donor' involved in this process."
>
> Organisation, National Gamete Donation Trust

In addition to these views focused on the range of options presented, some respondents comment more broadly on the information proposals. Three respondents criticise the wording of option 5 as apparently precluding a view on the appropriate information arrangements from those opposed to

the techniques. A few others argue in general that transparency around the procedure is important due to its newness and complexity, or that information provision should go beyond any of these options and include information on other parties involved.

> "The institutions making the plan, the society approving it, the parents requesting it, the donors participating must all be transparent to the offspring (and their descendants) who will have a social right to criticize their production. Social responsibility amounts to that kind openness."
>
> Individual, Other

8.2.4 Option 5

The majority of the very large number of respondents selecting option 5 revisit in their explanations the arguments against the introduction of the techniques they have made in response to earlier questions. 128 refer directly to another question. An additional 96 respondents selecting this option give no further explanation.

Some of those selecting option 5 go on to echo the criticism made by some selecting option 4, that only one option expressing opposition to the techniques limits the ability of those opposed to propose mitigating arrangements. Also, a small number of respondents criticise the label 'mitochondria replacement' as a misrepresentation of the MST and PNT techniques.

8.2.5 Other comments

There are a few other comments about information management made in responses to question 4b. Eight respondents who select various information disclosure options comment on the importance of donor screening. For most, the screening process, ensuring mitochondrial health and checking other potential problems, reduces the importance of keeping or sharing much information or the identity of the donor. In contrast, one respondent suggests there should be age and health restrictions on potential donors.

Some respondents simply note that retaining donor records would be important, mostly in anticipation of future health problems or in case of some other need to follow-up. A few comments are made about the legal implications of the procedures, one calling for more clarity before information rules are set, another suggesting the law could be altered to fit when the personal effects of the techniques on the child are clearer, and one querying how the donor's role will be legally recorded through the child's life.

Chapter 9 Question 5: regulation of mitochondria replacement

9.1 Headline findings

Question 5 asks:

> **If the law changed to allow mitochondria replacement to take place in a specialist clinic regulated by the HFEA, how should decisions be made on who can access this treatment?**

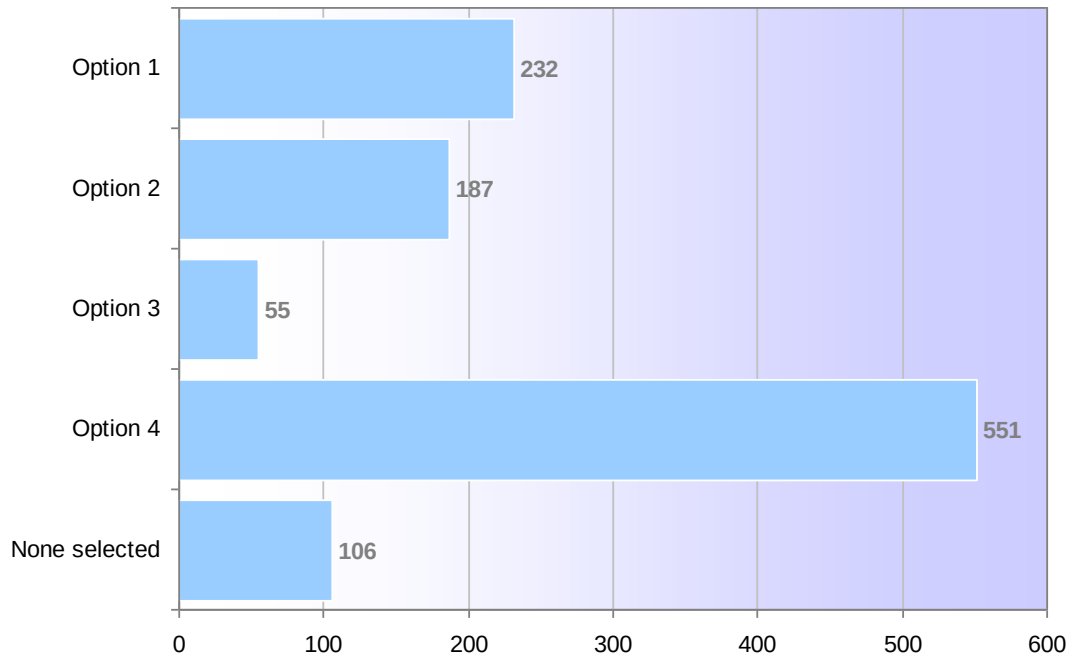
A total of 1,143 respondents answered this question. Respondents were given four options to choose from, and were asked to select one response only:

> **1) Clinics and their patients should decide when mitochondria replacement is appropriate in individual cases.**
>
> **2) The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and, just for these diseases, permit clinics and patients to decide when it is appropriate in individual cases.**
>
> **3) The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and also decide, just for these diseases, when it is appropriate in individual cases.**
>
> **4) I do not think mitochondria replacement should be permitted in treatment at all.**

Respondents were then asked to explain their choice.

A division can be made between options 1-3, which all propose a change in the law to allow mitochondria replacement treatment to take place with differing levels of regulation, and option 4, which states that the law should not be changed at all.

Figure 9 Options selected in responses to question 5



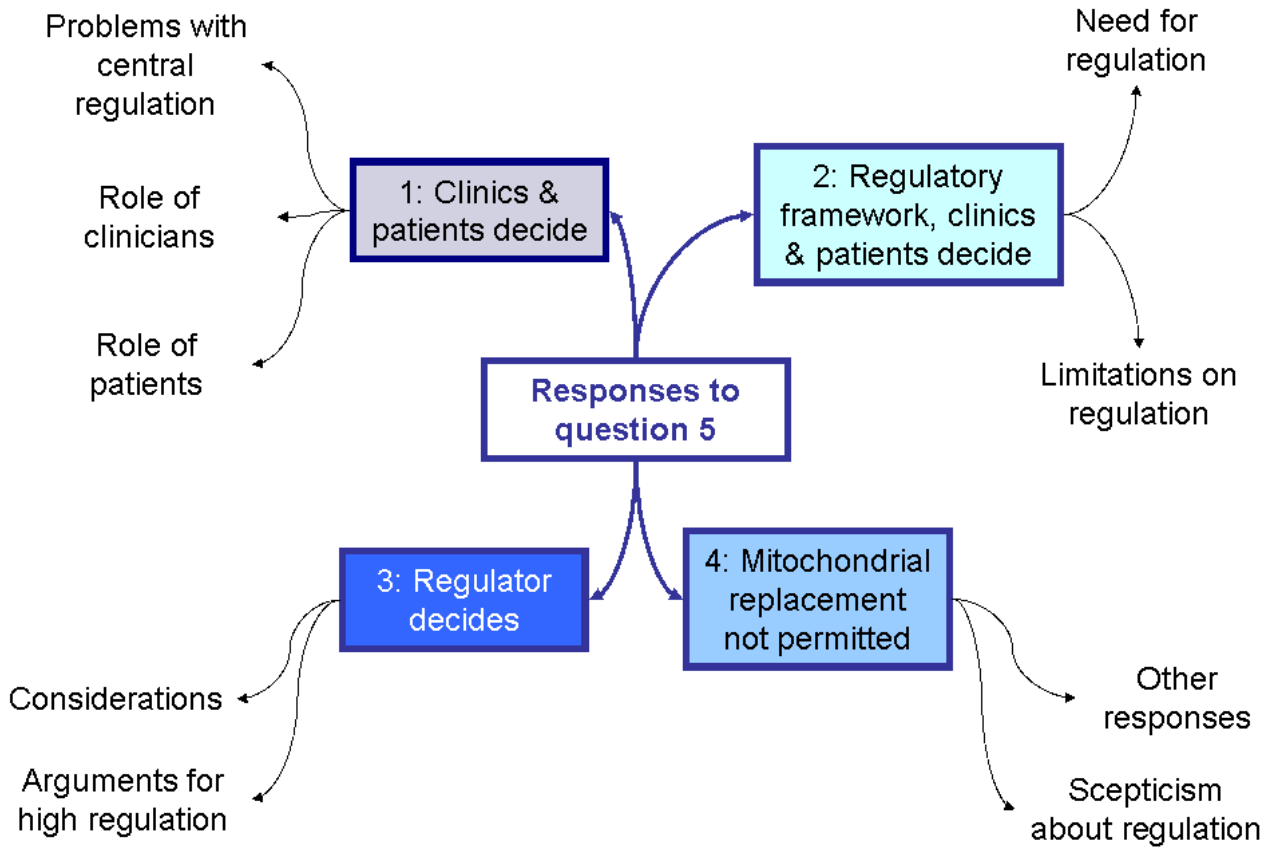
Of the respondents who selected options 1-3, the majority (232) selected option 1 (clinics and patients should decide when mitochondria replacement is appropriate in individual cases). Slightly fewer people (187) selected option 2 (a regulatory framework of diseases deemed serious enough to warrant mitochondria replacement, with clinicians and patients able to make decisions within this framework). Significantly fewer respondents (55) selected option 3, which calls for the highest level of regulation - an external regulatory framework with the regulator also responsible for making individual decisions within this. Just under half of the overall respondents (551) chose option 4, stating that they did not think mitochondria replacement should be permitted at all. The remainder of the respondents did not select an option, most leaving the question blank altogether, and a minority (11) writing general comments. People who left comments but did not select a response commonly said that they did not know, were unsure or had no strong opinion; several offered other suggestions for regulation, for example regulation by Parliament; and others simply reiterated their opposition to mitochondria replacement.

Among respondents who identify themselves as 'personally affected by mitochondrial disease' or 'family member or friend of a person affected by mitochondrial disease' option 1 is by far the most frequently selected option. Among respondents who identify themselves as 'student' or 'researcher' opinions are split between options 1, 2 and 4. Of the very few respondents who indicate that they are a member of staff of an HFEA licensed centre, three select option 1 and three select option 2. Among respondents who identify themselves as 'other' the great majority selected option 4 (see chapter 2 for an overview of respondent types).

There are a few stakeholder organisations in support of each of the options: option 1 is selected by the Association of Clinical Embryologists (ACE) Executive Committee among others; option 2 receives support from the Wellcome Trust, the Muscular Dystrophy Campaign and the Humanist Society Scotland; option 3 is favoured by the National Gamete Donation Trust and others; option 4 is selected by Comment on Reproductive Ethics (CoRE), the Anscombe Bioethics Centre and others.

In the second part of the question, respondents were asked to explain their choice. The reasons for these choices and the arguments surrounding them are explored in detail in this chapter under the following sub-headings:

Figure 10 Responses to question 5



9.2 Overview of comments

9.2.1 Responses to option 1 (clinics and patients to decide)

Option 1 states that 'Clinics and their patients should decide when mitochondria replacement is appropriate in individual cases'. This option proposes the lowest level of centralised regulation, with decision-making power devolved to the individual clinic level. Of the three options which allow for mitochondria replacement to take place (options 1-3), option 1 proved the most popular with 232 respondents indicating it as their preference. When respondents were asked to explain their choice, typical comments and arguments centred on issues of personalisation and the right to individual choice. Many respondents state their faith in the judgement of clinicians, while others focus on the rights of patients to play a central role in the decision-making process.

Problems with centralised regulation

Many respondents raise potential problems with centralised regulation to explain their preference for decision-making at the individual clinic level. The most common concern cited is that a central regulatory board would be rigid, inflexible and generalist, and would not be sensitive to individual circumstances. Many respondents feel that patients and clinicians are better placed to make decisions about the appropriateness of treatment, as they have a deeper understanding of individual circumstances and medical history.

> "ACE believes that clinics and their patients should decide when mitochondria replacement is appropriate in individual cases. This allows the expertise of specialist scientists and clinicians to be used to make these decisions rather than relying on a regulator who is unlikely to have the knowledge required to make the decision in an efficient or even appropriate manner."
>
> Organisation, Association of Clinical Embryologists (ACE) Executive Committee

Another concern respondents mention is that decision-making by a regulatory board would make the process too bureaucratic, expensive, or time-consuming. There are concerns around that centralised regulation would involve onerous levels of red tape and about the effect this would have on patients, particularly the level of distress that may be caused by added bureaucracy and time delays.

> "I would feel more comfortable with the decision being taken on a wider scale than just lying in the hands of one regulator."
>
> Organisation, The Lily Foundation

A number of respondents suggest that the nature of mitochondrial disease means that a 'list' of diseases qualifying for mitochondria replacement treatment would not be appropriate. Some point out that mitochondrial disease is extremely varied, and not all variations have been discovered and categorised. Even within established diseases, it is noted, symptoms can vary widely, and can be more or less serious in different cases. Some respondents therefore feel that maintaining a list of qualifying diseases would not be effective or useful, as the following quote illustrates:

> "As I understand it, mitochondrial disorders do not all fall into conveniently identifiable syndromes, and the same genetic fault might manifest in different ways. By their very nature, these diseases are inseparable from the distinct individual family stories of patients, and I believe that only they and their doctors can chart the right course."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

In relation to this point, some respondents raise concerns about the status of new or rare diseases, and suggest that a centralised list of diseases might delay treatment for diseases which had not yet been assessed or categorised by the regulator. One respondent described personal experience of this situation to argue against a regulated list of treatable mitochondrial diseases, which might deny sufferers of unidentified variants the chance of a child free of the disease.

Most of the respondents who chose option 1 feel that central regulation would not be sufficiently effective, efficient or sensitive to individual circumstances, and that clinicians would be better placed to make decisions on a case-by-case basis.

The role of clinicians

Many respondents argue that clinicians have the most familiarity with the individual circumstances and medical history of their patients, and are therefore best placed to make decisions about their treatment. The varied nature of mitochondrial disease, some respondents note, means that it is necessary to take into account the medical history of the individual and their family in establishing the best course of treatment.

Other respondents add that if practitioners are sufficiently well-trained and qualified there should be no need for external regulation.

The role of patients

Many respondents feel that it would be important for the patients themselves to have a central role in the decision-making process. The majority of respondents who selected option 1 feel that a joint decision, made between patients and their doctors, would be the most appropriate. Many argue that individual patients know their own circumstances better than anyone else, and are therefore best placed to make decisions about what is right for themselves and their families.

An argument put forward by several respondents is that it is impossible to set an objective measure on what constitutes a serious disease. The experience of disease, it is argued, is subjective and personal – disease may be experienced as 'severe' to different degrees depending on the circumstances of the individual. The following personal vignette illustrates this point:

> "Only the patient can identify the severity of their symptoms… I have a disfiguring disease in my family that has led three members to avoid having children. Some might say the condition wouldn't warrant them refusing to have children with a 50/50 chance of contracting the condition, but they have lived it, they have had the operations to attempt to correct it, they've suffered the bullying in school and feeling different as a child. Only the parents can say how severe their condition is to them."
>
> Individual, Student

It is therefore problematic, some respondents argue, to set an external, objective regulatory standard of what constitutes sufficient severity for treatment, and instead necessary to maintain a more flexible system which allows for individual circumstances.

Similarly, some respondents argue that treatment should be widely available and not restricted to patients with the most serious illnesses only. They argue that everybody has the right to a life free from disease, and that it should not be left to a regulatory board to decide which diseases are serious enough to qualify for treatment. A number of respondents invoke an equality principle, arguing that if the treatment were made available to some patients it should be available to all.

Four respondents who chose option 1 cited personal experience of mitochondrial disease, stating that either they, or a family member, had suffered from the disease. Of these respondents, two argue that all mitochondrial disease was serious for those affected, and they do not believe that treatment should be restricted only to diseases deemed to be most severe. The other two respondents explain their choice on the grounds that the disease of which they have experience is rare and may not be covered by regulatory guidelines.

9.2.2 Responses to option 2 (regulatory framework; clinics and patients decide)

Option 2 states that: 'The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and, just for these diseases, permit clinics and patients to decide when it is appropriate in individual cases.' Slightly fewer respondents (187) selected this option than option 1. Most respondents who chose option 2 emphasise that they believe clinicians and patients should have an important role in the decision-making process, but also feel that there is a need for some level of external regulatory framework. Some respondents specify that they think more regulatory oversight will be needed when the techniques are first used.

The need for regulation

A number of arguments are made for the need for a level of central regulation. Many of these arguments are based on the need to prevent abuse or overuse of mitochondria replacement treatment, and ensure that it is used only when medically appropriate and necessary. The 'slippery slope' argument, familiar from previous questions, resurfaces in response to this question. Some respondents argue that allowing mitochondria replacement could potentially open the gates for the rise of eugenics or 'designer babies', and that regulation is necessary to ensure that the treatment

is used responsibly and appropriately. Others suggest that regulation is necessary to guard against profiteering on the part of private clinics, who might be inclined to offer the treatment when not strictly necessary. Some respondents feel that the treatment, particularly in the early stages, should be used to treat those most severely affected by mitochondrial disease only, and that regulation is necessary to limit the application of the treatment:

> "The technique should be regulated so it is only permitted for certain serious diseases. This would avoid it being labled [sic] the 'slippery start of the slope' and also protect families from inappropriate/unnecessary treatment if there is no good clinical benefit to outweigh the risks."
>
> Individual, Other

Another set of arguments is based on the need for centralisation to ensure fairness and equity in the provision of treatment. Some respondents feel that a central regulator is the fairest way of distributing treatment, and making sure all applications for treatment are judged according to the same criteria. Some respondents raise concerns about the possibility of a 'postcode lottery', and argue that central regulation is necessary to ensure fairness.

A small number of respondents argue for central arbitration on the ethical questions raised by mitochondria replacement. They suggest that the complexity of the ethical questions involved means that different individuals are likely to have very different views on to what extent and when treatment is appropriate. Central regulation is therefore necessary, it is suggested, to mitigate against the subjectivity of individuals, and to ensure the same ethical standards, for example definitions of the rights and moral status of unborn children, are applied in all cases.

Several respondents draw a parallel between the regulation of mitochondria replacement treatment and Pre-implantation Genetic Diagnosis (PGD). The British Fertility Society calls for regulation of mitochondria replacement treatment to follow the model of regulation of PGD, with a regulator responsible for deciding which diseases are serious enough to warrant the treatment:

> "The BFS is of the opinion that the regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement in line with current approvals for Pre-implantation Genetic Diagnosis, and permit clinics and patients to decide when it is appropriate to treat for these disorders in individual cases."
>
> Organisation, British Fertility Society

The Association of Medical Research Charities (AMRC) and Genetic Alliance UK echo the views of the BFS on the need for centralised regulation on which diseases should receive treatment, and also offer some suggestions for how these diseases should be identified:

> "In reaching a decision on the severity of mitochondrial diseases we believe the regulator should follow the principles used in the regulation of PGD, such as peer review, use of an experienced standing committee, and of stakeholder input."
>
> Organisation, AMRC and Genetic Alliance UK

Limitations on regulation

A number of issues and suggestions are raised regarding the role of the regulator, and the limitations which should be placed on centralised regulation. Many respondents emphasise that while they feel that some centralised regulation is necessary, they do not believe that a regulatory board should be responsible for making individual decisions (as proposed in option 3). The reasons for this tend to be similar to those cited in option 1. These respondents argue that it would be too bureaucratic, impersonal and time-consuming for the regulator to be involved in decisions

about individual cases. As in option 1, many respondents state that clinicians are best placed to make decisions in individual cases, and that the individual patient should have an important role in the decision-making process. It is frequently emphasised that clinics and patients should be given the freedom to make decisions about treatment within the parameters set by the regulator:

> "It seems unnecessarily bureaucratic and intrusive for a regulator to review individual cases but equally some central, disinterested guidance in what diseases should be treated seems sensible."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

A number of respondents feel that higher levels of regulation would be necessary in the early stages due to the uncharted nature of the treatment, but suggest that central regulation could be relaxed once the procedures were more established if they proved to be safe and effective.

Several respondents call attention to the need to keep regulation up to date as new diseases are discovered and new scientific developments occur. These respondents argue that the regulatory body should also be subject to monitoring and review to ensure that it keeps step with evolving knowledge of mitochondrial disease.

9.2.3 Responses to option 3 (regulator decides)

Option 3 proposes that: 'The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and also decide, just for these diseases, when it is appropriate in individual cases'. This option proposes the highest level of centralised regulation, suggesting that an external regulator should be responsible not only for providing a regulatory framework, but also for adjudicating in individual cases. This was the least popular option, with significantly fewer (55) respondents choosing it than options 1, 2 or 4. Of the respondents who did choose option 3, many said that they did not think that the law should be changed to allow mitochondria replacement treatment, but that if it were they would choose option 3, as it offered the most intensive regulation of the treatment.

Arguments for high regulation

A number of arguments for high levels of regulation are put forward by respondents to this question. Many of these are similar to those addressed in option 2. As in option 2, a number of respondents argue that because of the nature of the treatment it should only be offered in the most serious cases, and that it is necessary for an external body to determine what these cases are. Many respondents report concern about the treatment being overused, and argue that central regulation is necessary to ensure that the treatment is used only when medically necessary and appropriate. As in option 2, many respondents raise concerns about private clinics being driven by a profit motive to offer the treatment in inappropriate cases, and argue that high levels of regulation are necessary to guard against this. The issue of bias or partisanship on the part of clinicians is also raised. Some people suggested that individual doctors might be biased by a personal relationship with a patient, or pressured by patients and their families, into offering treatment which was not appropriate:

> "I think this area needs strict regulation to maintain public confidence, and that this extends to individual cases. I am in favour of the use of the technique and would not like to see it potentially mis-used due to pressure from patients or clinics."
>
> Individual, Other

It is therefore necessary, some respondents argue, for decisions about individual cases to take place at a centralised level, to ensure impartiality and guard against partisanship.

As in option 2, several respondents suggest that high levels of centralised regulation are necessary to safeguard equity and fairness. Concerns about a 'post code lottery' resurfaced, with a number of respondents expressing unease about differential access to treatment. Respondents suggested frequently that a centralised decision-making body would be a fairer and more effective mechanism for allocating treatment.

Considerations

Some respondents add further comments and suggestions about the role of the regulator. Several suggest a flexible model of regulation in which treatment would be highly restricted and monitored at first, but could be relaxed over time, with more decision-making power devolved to clinicians, if the treatment proved to be safe and effective.

A number of respondents mention the need for the regulator to conduct long-term follow-up on the effects of the treatment. Some respondents cite the need for long-term review of the medical consequences of the treatment, suggesting that changes to the germ line could create unpredicted effects on future generations, which would require careful monitoring. Others cite the need for follow-up research to monitor the social and psychological consequences of the treatment for the patients and their families. The Project Group of Assisted Reproduction (PROGAR) offers some suggestions for how this follow-up research should be carried out:

> "Regulation and associated research must, in our view, include central attention to psycho-social as well as medical, scientific and developmental psychology aspects. Research must include social science qualitative research, including longitudinal, to capture nuance, ambiguity and meaning to the parties directly concerned."
>
> Organisation, PROGAR

The role of the regulator, it is suggested, is not only to make decisions about which diseases qualify for treatment, but also to research the broader and more long-term implications of mitochondria replacement.

9.2.4 Responses to option 4 (mitochondria replacement should not be permitted)

Option 4 states: 'I do not think mitochondria replacement should be permitted in treatment at all'. It differs from options 1-3, allowing respondents to register their opposition to mitochondria replacement, particularly if this meant that the other options are not relevant to them. About half of those responding to the question (551) selected option 4. Respondents tend to reiterate arguments made in response to earlier questions, particularly question 1. Many simply direct the reader to refer to their previous responses; others reiterate or elaborate on their opposition to mitochondria replacement treatment. This section will discuss responses directly related to regulation only – wider arguments against mitochondria replacement can be found in other chapters.

Scepticism about regulation

Many respondents who selected option 4 are sceptical about either the relevance or the effectiveness of regulation. A substantial proportion of respondents (38) state that no level of regulation could make mitochondria replacement acceptable because it is fundamentally unethical:

> "I do not think mitochondria replacement should be permitted in treatment at all because regulating or licensing unethical action does not make it right."
>
> Individual, Other

These respondents often go on to reiterate ethical arguments against mitochondria treatment, or direct the reader to refer to their previous answers.

Others respondents raise concerns about the effectiveness of regulation, or state their scepticism that strict regulation would be maintained in the long term. Some specifically cite their lack of trust in the HFEA. There is a concern that regulation tends to relax over time, and some respondents feel that even if treatment were strictly regulated at first, regulation would gradually become less stringent and treatment more widely available. Some respondents referred to historical precedents of regulations which have become less stringent over time. Several used the regulation of abortion as a comparative example, as the following quote illustrates:

> "Political safeguards are as reliable as chocolate teapots. When abortion was first legalised we were told that strong safeguards would be put in place in order to eliminate abuse. These so-called safeguards were watered down, or totally ignored, as the years went by. What we now have, in effect, is abortion on demand. The same would happen with the procedures under discussion. Any safeguards would, over the years, be watered down and then ultimately ignored."
>
> Individual, Student

Most respondents who selected option 4 feel that regulation would be inappropriate or ineffective and therefore feel that the law should not be changed to allow mitochondria replacement at all.

Other responses

A small number of respondents who selected option 4 on the grounds that they did not want the law to be changed also indicate what kind of regulation they would choose if the law were to change. Of these respondents the majority say that they would choose option 3, on the grounds that this proposes the strictest level of centralised regulation. Four respondents say that they would choose option 2.

A number of respondents suggest that if the law were to be changed, regulation should take place at a parliamentary level. Many of these respondents cited a lack of trust in other regulatory safeguards, and raised concerns about the slackening of regulation and expanding use of techniques over time. The following quote illustrates this perspective:

> "I have no confidence in regulatory bodies, as their recent history has been lamentable. Should such techniques be approved at all, I think their [sic] should be a clear set of laws limiting them, saying both what is allowed and what is not, debated and passed in parliament, with no room for ambiguity, interpretation or other erosion. The regulator's role should be to enforce the law, not interpret or soften it, or campaign for its creative reinterpretation etc."
>
> Individual, Student

Respondents who advocate for parliamentary regulation tend to feel that regulation enshrined in law and overseen by Parliament would be more stringent and effective, and therefore preferable to other forms of regulation.

Chapter 10 Question 6: should the law be changed?

10.1 Headline findings

Question 6 asks:

> **In Question 1, we asked for your views on the mitochondria replacement techniques MST and PNT. Please could you now tell us if you think the law should be changed to allow (one or both of) these techniques to be made available to people who are at risk of passing on mitochondrial disease to their child?**

1,055 people responded to this question.

The overall views of respondents in response to this question broadly reflect the views about acceptability expressed in response to question 1. Overall, 558 respondents commenting on question 6 oppose a change of law. A further 316 of respondents indicate that they support a change in the law, and 82 say that they would if their caveats are addressed. A few respondents think the law should only change for one of the proposed techniques. Only 7 respondents do not express an explicit opinion either way on whether or not the law should change, instead discussing related issues and considerations.

That the numbers reported above are not completely equal to those of respondents arguing in favour or against the techniques in their responses to question 1 is mainly a consequence of the fact that not all respondents answered all consultation questions. There are fewer than a handful of respondents each way whose comments about changing the law (question 6) are seemingly conflicting with their comments about the acceptability of mitochondria replacement techniques (question 1). Additionally, six respondents who say in response to question 1 that the techniques are acceptable if certain conditions are met subsequently argue against a change in the law when responding to question 6.

Respondents who indicate that they are personally affected by mitochondrial disease are overwhelmingly in favour of a change in the law. The same is true for respondents who indicate that they are a friend or relative of someone affected by mitochondrial disease. All in all around 95 respondents from these categories make comments in favour of a change in the law, with a dozen saying they are in favour subject to caveats.

Of respondents who indicate they have personal experience with gamete donation or donor conception, 13 say they are in favour of changing the law and three state the opposite.

Organisations in favour of changing the law include the Wellcome Trust, the Muscular Dystrophy Campaign and the Humanist Society Scotland. The British Medical Association, the Academy of Medical Sciences, the Association of Medical Research Charities and the Genetic Alliance UK, and the British Fertility Society support a change in the law in principle, but make caveats. Human Genetics Alert, the ProLife Alliance and others are against a change in the law.

Non-questionnaire responses

A number of the 503 non-questionnaire responses contain comments about changing the law. Many of these comments are made in responses that follow a similar structure and make a range of similarly worded points. More than 200 emails and letters include a statement against a change of the law. In many cases these comments are accompanied by references to legislation in other (EU) countries, with respondents expressing concern that the UK would be the first country to cross a boundary and allow techniques that are illegal elsewhere. There are a few letters and emails with comments endorsing a change of the law.

Those respondents opposing a change in law tend, as with question 1, to focus largely on ethical concerns such as the use of embryos, and interference with the natural or spiritual aspect of reproduction.

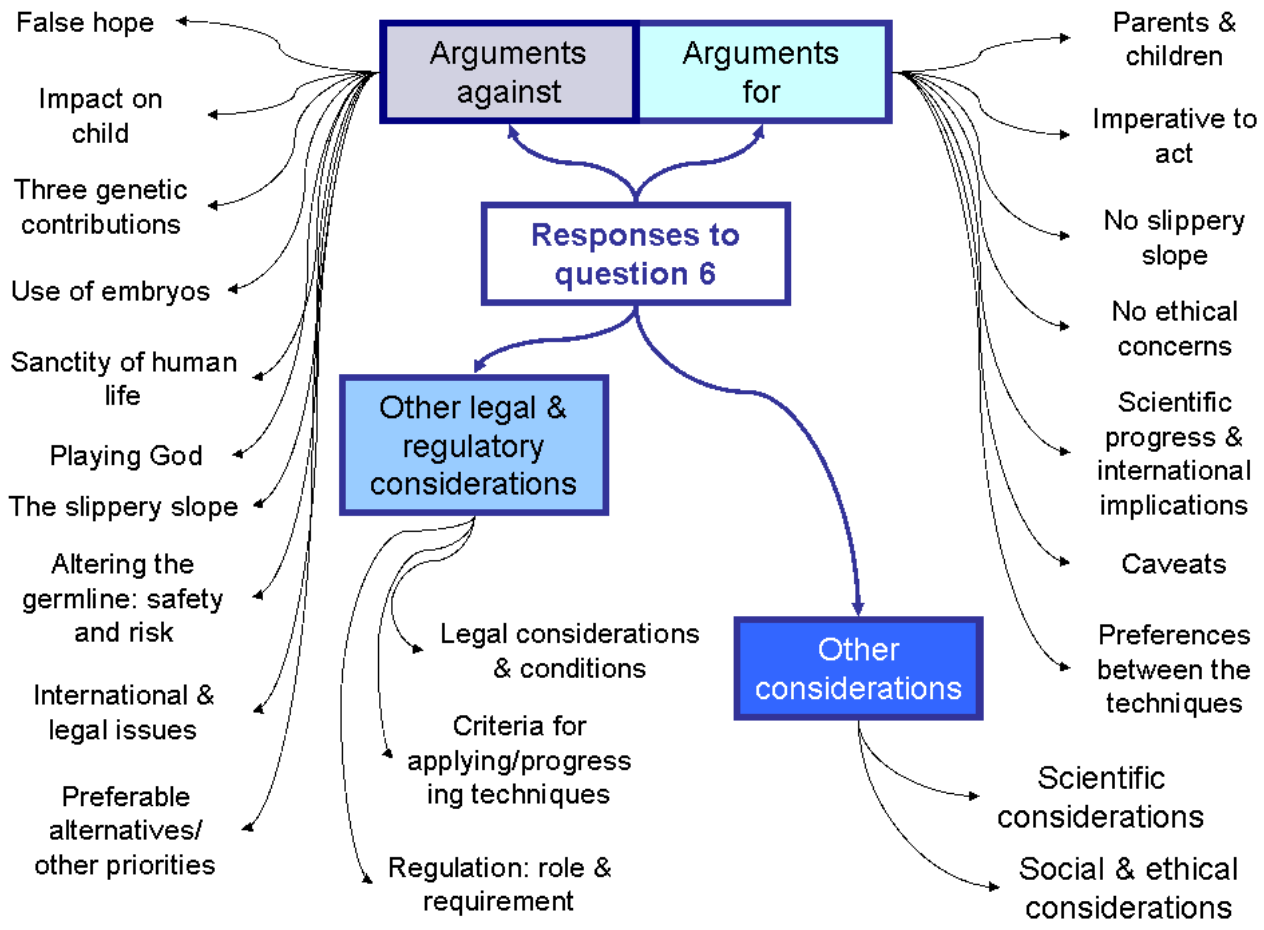
Several respondents mention a preference for other alternative approaches to addressing mitochondrial disease; others express concerns about unknown consequences. There are also concerns expressed about the slippery slope, as well as references to these techniques not currently being legal in other countries.

Those respondents supporting a change in law tend to focus primarily on the benefits the treatments could provide, particularly disease avoidance and the opportunity for parents to have a healthy child, with several discussing the impacts of mitochondrial disease on sufferers and their families. Others talk about the ethical imperative to intervene, again as in previous questions.

Where a preference is expressed for one technique in particular, this again tends to be for MST over PNT, as respondents note that this technique uses eggs rather than embryos. In total, 21 respondents state that the law should be changed to permit MST, and a further 10 agree with a caveat, compared to just one arguing for the law to change to permit PNT. Meanwhile 22 respondents argue that the law should not change to permit PNT, while none make the same case against MST.

These arguments and others raised by respondents to question 6 are explored in more detail under the subheadings reviewed below:

Figure 11 Responses to question 6



10.2 Overview of comments

10.2.1 Arguments against a change in law

A total of 244 respondents say that they oppose a change in law to allow one or both of the two techniques but do not explain their opposition. A number of respondents refer back to supporting arguments made in response to previous questions and some give a fuller explanation in of their opposition to a change in law in response to question 6, as summarised here. Some of these respondents make it clear that they have sympathy for those affected by mitochondrial disease but still oppose a change in law for many of the reasons outlined below.

Use of embryos, sanctity of human life, playing God, overall ethical issues

As with question 1, the most commonly cited argument against a change in law is that the creation and destruction of human embryos involved in these techniques (often specifically in PNT) is unethical (75). A number of comments relate to this point. These include points about the sanctity or dignity of human life being jeopardised by these techniques, as well as concerns that these techniques interfere with natural reproductive processes or would involve humans playing God.

> "I object to the techniques themselves, since they involve the discarding of embryos. Human life should be respected and yet these techniques are promoting the destruction of life."
>
> Individual, Other

Other respondents say there are simply too many ethical or moral concerns, with a small number of comments that the end does not justify the means.

> "The very fact that there are strong ethical arguments against these procedures and a large lobby against them should make the government very cautious indeed about permitting research to advance in this direction."
>
> Individual, Other

Preferable alternatives and other priorities

Several respondents, many using similar wording, state that there are other preferable alternatives for the treatment or cure of mitochondrial disease, which should be pursued instead of these techniques (63).

> "Other methods (such as repairing faulty mitochondria) are already being developed by scientists and should be examined further instead of considering PNT and MST."
>
> Individual, Other

Other respondents comment that people do not have an automatic right to a healthy and/or genetically related child; in relation to this, a number of other preferred options for at-risk parents are cited, including adoption, a decision not to conceive, counselling or support, and use of donor eggs.

A few respondents suggest (and these suggestions tend to be general rather than specific) that there are more pressing issues that should receive focus and/or funding over and above the progression of these kinds of techniques.

Altering the germ line: safety and risk

The unknown future risks, impacts or unintended consequences of these techniques are also cited as arguments against their legalisation (57). Many of the comments made are general, for example mentioning 'potential problems', 'complications', 'serious risks', 'impacts on future generations' and so on; they also focus on both individual (e.g. health risks) and overall societal risks or impacts.

> "As the risks are unknown & the potential for harm in various parameters (social etc) is high, the law should not be changed."
>
> Individual, Other

Some respondents say explicitly that the costs or risks of these techniques would outweigh the benefits; others talk about the impact of altering mitochondrial DNA on the germ line or genetic lineage or say that altering DNA is simply not acceptable, with some offering the view that these techniques involve cloning or hybridisation as a supporting argument for not changing the law.

International and legal issues

A number of respondents, many using similar wording, note that outside the UK these techniques are not legal or can incur prison sentences. The UK would thus be the first country to cross this particular ethical boundary. Others state that the legalisation of these techniques would contravene international (for example EU or UN) law. A small number of respondents add that the UK should not be allowed to make a decision which could have a global impact.

> "No, the law should not be changed. If it were, the UK would become the only country in the world to legalise such procedures and this is one area where there seems to be no benefit in being out on a limb."
>
> Individual, Other

A few respondents go further in saying that they think the law should be made stricter, for example by restricting the application of existing techniques involving embryos or to further discourage research into or development of any potential new techniques.

The slippery slope

As in their responses to previous questions, respondents raise both general and specific concerns about the introduction of these techniques. Some see them as the start of a slippery slope with negative consequences at its end. Others mention designer babies or commodification of the human, eugenics, cloning, and the normalisation of genetic modification as specific concerns.

> "If we permit these procedures which manipulate genetic information, it is possible that future genetic 'treatments' for cosmetic reasons will become acceptable."
>
> Individual, Other

Three genetic contributions, impact on child, false hope

Again, as with previous questions, respondents raise concerns about these techniques involving genetic material from three people. Many of these are related to worries about interfering with natural reproductive processes or playing God by creating 'three parent families'; others mention concern for the child's sense of identity, and for their general or psychological wellbeing, as well as the potential for valuable individuals to be lost as a result of these techniques.

> "We do not know what the psychological effects will be on a child when they learn they have three or four parents...
>
> …The sanctity of human life is upheld throughout the Bible. It is very clear that God intends human beings to have two parents – a mother and a father."
>
> Individual, Other

Some respondents question whether the techniques would actually work, suggesting that they would present 'false hope' to parents at risk of passing on mitochondrial disease, while others comment that these techniques are not a cure or will not necessarily eradicate mitochondrial disease.

10.2.2 Arguments in favour of a change in law

A total of 170 respondents say that they would like the law to change to allow one or both of the two techniques without explaining their view. A few of respondents refer back to supporting arguments in response to previous questions and some respondents give a fuller explanation of their support in their response to question 3, as summarised here.

Parents and children

As with question 1, the most frequent argument in favour of legalising these techniques cites the importance of the health of the child, with the avoidance of mitochondrial disease being passed on, or even its eradication, being seen as a positive step.

Some respondents talk about the impact of mitochondrial disease not only on the sufferers themselves, but also on the parents and families of sufferers, several making reference to personal experience. A number of related comments refer to the benefits of these techniques for potential parents and families overall, for example through offering parents an opportunity to have a child without the worry of mitochondrial disease being passed on. A few respondents state that they think parents have a right to a healthy and/or genetically related child, which these techniques would enable.

> "I believe mitochondria replacement to be the human right of the unborn children of women whose damaged mitochondria are likely to manifest in their serious ill health. The progressive and often terminal course of the conditions linked to these mitochondrial abnormalities have a devastating impact on the person and those who love and care for them.
>
> I have watched my oldest friend deteriorate from a fun loving, happy child and teenager to an often angry, frightened and confused 30 year old who experiences drop-seizures daily and is now entirely dependent on her parents. The multi-systemic difficulties associated with mitochondrial conditions are often of late onset and families embark on a harrowing journey where they must try to adapt to each new stage of the disease before the next progression…"
>
> Individual, Family member/friend of someone affected by mitochondrial disease

Ethical imperative to act, not a slippery slope, no concerns

The imperative to intervene if the ability to do so exists is again given as a supporting argument for allowing these techniques.

> "Both of these techniques should be made available to all who have need for them. It is unethical to have the technology and not to use it."
>
> Individual, Student, Researcher

Some respondents state that they think the techniques are safe, have an acceptable level of risk, or that the benefits outweigh the risks. A few state explicitly that they have no ethical concerns or, more specifically, no concerns about these techniques representing the start of slippery slope with a negative end. In support of these statements, a small number of respondents point out that these techniques are different to those required for designer embryos or cloning (for example because nuclear DNA is not altered) or that regulation should prevent this from setting the precedent for other techniques they might find unacceptable.

Scientific progress and international implications

A few respondents talk about the development of these techniques being a positive or important scientific advance or natural progress.

> "These procedures are hope. They would be a dream come true. They signify years of research & the new ability to overcome genetic disease with amazing technology."
>
> Individual, Other

Related to this are comments about the need to change the law quickly to enable the benefits of these techniques to be felt as soon as possible, and the potential for the UK to be a leader in this new area of science. A small number of respondents talk about the international aspects of these techniques, for example the suggestion that other countries would introduce these techniques if the UK did not and that UK patients or expertise may end up overseas.

Caveats for changing the law

A number of respondents expressing support for a change of law either for both techniques or for MST do so only under the condition that certain caveats are met. These caveats tend to focus on specific criteria for the application of the techniques, the need for regulation, and specific legal considerations or conditions – these are covered in section 10.2.3 below. Other caveats include the need for further research, trials or evidence should these techniques progress, and the expression of a preference for MST over PNT should both techniques be found to be equally

viable. Indeed, the most common caveat for those supporting a change in law for MST only is that PNT be explicitly disallowed.

> "Yes both techniques should be available initially, until such data is available to either favour one technique or establish that neither is a worthwhile avenue of treatment. This may necessitate all treatments being part of a national surveillance/tracking project to collect this data as part of a trial period."
>
> Individual, Researcher

Preferences between the techniques

As discussed above, where there is a preference for one technique to be legalised over the other, the preference falls with MST over PNT. The arguments in favour of MST over PNT tend to focus on the respondent having fewer ethical concerns about MST because of the use made of embryos in PNT.

> "I am in favour of MST because what I have read leads me to believe that the underlying genetic makeup or essence of a person would not be changed i.e. they would be the same person they would always have been except for the sole exception that their cells would work properly. Thus they would have an improved quality of life (as may their families) and no real identify confusion. The procedure would be equivalent to a transplant.
>
> At the moment I am uncomfortable with PNT because two embryos are created meaning two lives could be viewed to have started yet one of them is given no chance to live and is sacrificed for the other. While others would argue an embryo is not really a life until it is several weeks old (the thinking that makes aborting permissible) I have never been comfortable with it."
>
> Individual, Other

10.2.3 Other legal and regulatory considerations

Other legal considerations and conditions

The Human Fertilisation and Embryology Act is mentioned a number of times in responses to this question. These response include remarks on individual respondents' understanding of what the Act does or does not provide for in relation to this particular issue; for example that these kinds of techniques were banned under the original Act, that the Act is ambiguous, or that it does indeed provide for the development of such techniques.

Some respondents have other comments or queries about the law in relation to this topic, or the legal system more generally. These include: whether a change in law is needed; the difficulty of creating a law with no loopholes; the relationship to Scottish law; and the need for the law to protect human rights or human embryos.

Others provide suggestions for specific details, should the law be changed. These include: suggestions that the law should show a preference for a particular technique (e.g. MST in the first instance) or that the law should not specify particular techniques; comments on which diseases or types of diseases should be written into law; a comment on specifying the origin of donor DNA by law; comments on the need for careful drafting and specification of boundaries (for example specify the techniques are to be used for the treatment of mitochondrial disease only) to prevent abuse; the need for a central database of donor information; and suggestions for other changes in law in related areas of fertility and embryology.

A few respondents suggest specific legal conditions, including: only allow PNT in specific circumstances, only allow testing or trials in the first instance, allow one technique only (either,

depending on the evidence). Others say that further exploration is needed, either generally or of PNT specifically, before any change in the law is considered. These conditions or requirements are often given as caveats to support for a change in the law.

Other comments on the legal system include various comparisons with other procedures or donation types, the suggestion that the law could be re-visited after a set period if needed, and a couple of comments stressing that the law does not have a place in these decisions ahead of patient or professional choice.

Criteria for applying or progressing techniques

When it comes to deciding which technique/s should be progressed to clinical use and made available to potential parents, respondents suggest a number of criteria for deciding whether to progress a specific technique, to help choose between the two techniques or to help with a decision about which cases they should be used for. The most commonly mentioned criterion is safety, closely followed by the efficacy or efficiency of the technique. Other criteria include medical evidence or advice, cost or value, patient need or appropriateness, as well as a number of other suggestions.

> "PNT raises more problems for me, considering that is involves the destruction of potentially viable embryos. However, on the assumption that this would be performed at a very early stage, it might well be that the benefits are worth the worry if it becomes evident that PNT is safer and/or dramatically cheaper than MST."
>
> Individual, Student

Several respondents talk about criteria for who decides rather than on what basis the decision is made. For example: it should be down to the parents or the parents and clinician together to decide which technique if any to use; the decision should be down to 'scientists'; to the regulator, or to parliament. A small number of respondents suggest that there should be no criteria or that the technique should be open to anyone who wants it.

In relation to the point about availability, there is also a small number of comments about the need for equitable provision or ease of access should these techniques become publicly available. A few respondents comment on funding and between them offer opposite arguments: that the NHS should cover these techniques, or that it should not and they should be funded privately by individuals.

Regulation: role and requirement

A small number of respondents note a distinction between regulation and ethical acceptability, stating that the former does not entail the latter. One respondent notes a general lack of trust in the regulators. Aside from these comments, most of those discussing regulation in response to question 6 focus on two areas: the need for regulation and the specific roles of the regulator.

Comments on the need for regulation tend to be at a general level, i.e. regulation is needed should these techniques become legal; several respondents here use words such as 'suitable', 'strict', 'close' and 'careful' to stress the level of regulation which they feel would be required. Suggestions of specific roles for the regulator include the following: enabling provision to high-risk patients; monitoring safety; setting boundaries, producing guidelines and preventing abuse such as non-medical usage; assessing and licensing clinics; and maintaining a register of applicable diseases.

> “As I stated, all these techniques have come about as a result of our ability to improve and advance ourselves. An old saying about ‘once the genie is out of the bottle...’ comes to mind. In that light I feel all of these options should be legalised and available but again under strict control from the regulator.”
>
> Individual, Other

10.2.4 Other considerations

Scientific considerations

Aside from the comments about scientific progress and further research outlined in 9.2.2 above, there are relatively few comments on the scientific aspects of MST and PNT compared to responses to other questions, perhaps because respondents tend to focus on the wider social and ethical arguments for or against progressing these techniques. A few respondents mention mitochondrial function and other procedures such as IVF; others talk about progress in either a cautious (for example, that there is a lack of understanding, proceed with caution) or a positive (for example expand this type of research to other diseases) light, with a small number suggesting that science should prevail or take precedence in decision making.

Social and ethical considerations

The number of respondents to question 6 commenting on social and ethical considerations in a more neutral manner tends to be relatively low, with most using ethical and social arguments to support their views about whether or not the law should be changed. Those respondents who do mention social and ethical issues in a more neutral manner tend to reflect on issues already covered in response to other questions. These include reflections on the rights of embryos or eggs, availability of donors, follow-up studies or monitoring, information provision and support to parents and donors, and consideration of the number of people who would benefit from these treatments.

Chapter 11 Question 7: further considerations

11.1 Headline findings

A total of 883 respondents answered question 7 which asks:

> **Q7: Are there any other considerations you think decision makers should take into account when deciding whether or not to permit mitochondria replacement?**

Respondents answering question 7 tend to use their response as an opportunity to do one or more of the following: reiterate arguments for or against taking forward the two techniques; discuss additional considerations they would like decision makers to take into account; or consider the wider context and overall decision-making process.

Arguments for and against the further progression of MST and/or PNT largely echo those expressed previously in response to other questions, with arguments against tending to concentrate on crossing boundaries or the creation and destruction of embryos, and arguments in favour focusing on the benefits to those at risk of passing on mitochondrial disease.

A number of the additional considerations raised by respondents in response to question 7 are also familiar from responses to previous questions, for example those focusing on social or ethical dilemmas and implications. However, there are some specific areas that receive more attention here. These include more detailed comments about the practicalities of taking forward these techniques, for example questions of regulation and criteria for application, as well as other comments about the nature of science and the need for further research and monitoring.

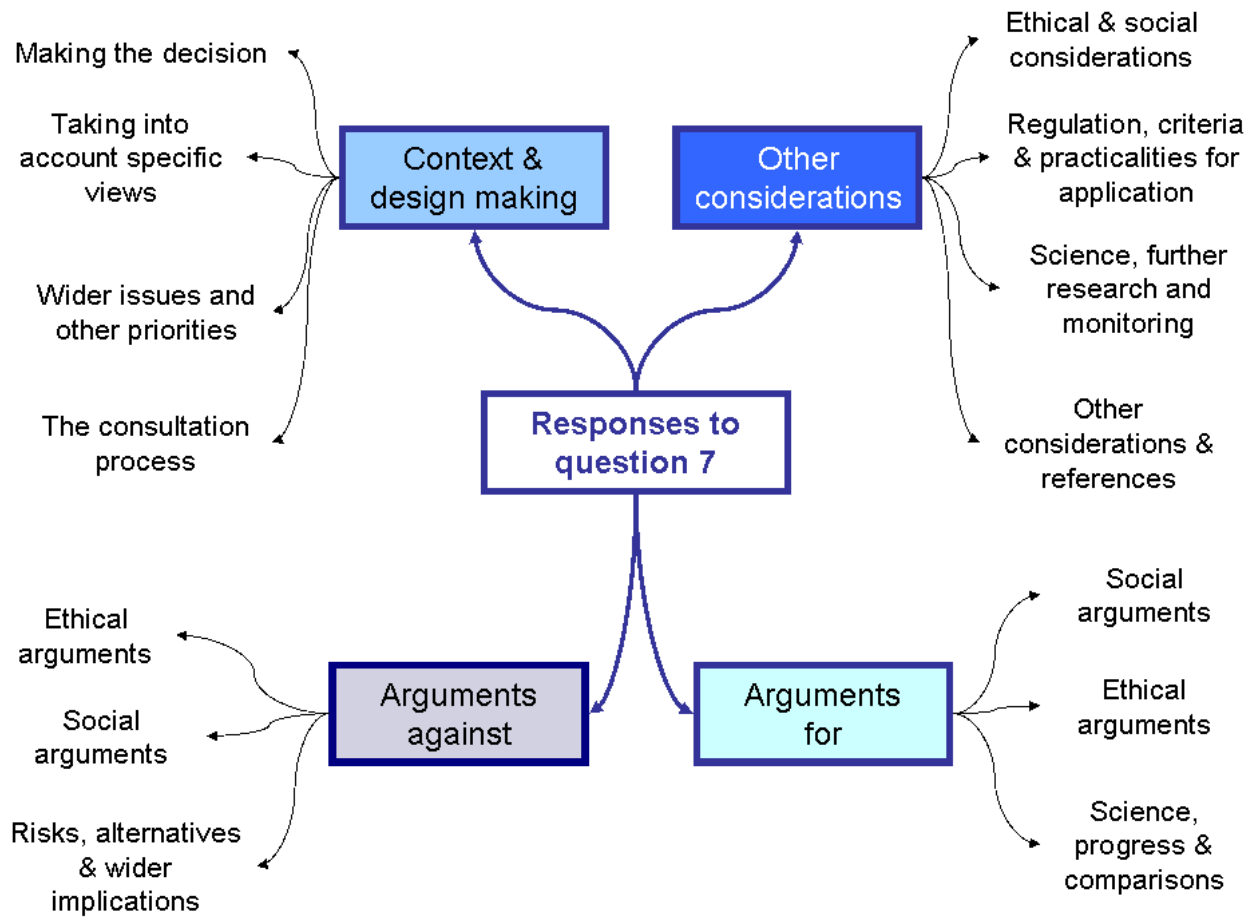
Those respondents who talk about the wider context or the decision making process in response to question 7 cover a range of issues. Some talk about the nature of the decision and the basis on which it should be made, for example with ethics at the centre, or with science at the centre. Others point out that there are wider issues that would benefit from discussion, or other priorities that require focus. A number of respondents ask that decision makers specifically consider the views of certain groups, or do not give undue weight to others. There are also some comments about the consultation itself, both positive and negative.

Non-questionnaire responses

In some of the 503 non-questionnaire responses there is mention of other treatments of mitochondrial disease, which respondents say are emerging. Overwhelmingly these comments are part of a range of similarly worded points which can be found in around 300 emails and letters. The point respondents make about other treatments is that (research into) these should be prioritised over mitochondria replacement. No specific reference is made as to what these other treatments are, or where they are being developed.

Responses to question 7 are explored in more detail in this chapter under the subheadings summarised below:

Figure 12 Responses to question 7



11.2 Overview of comments

11.2.1 Arguments against the introduction of the techniques

In response to this question some respondents simply state their opposition to the techniques or for a change in law, while others focus on outlining their reasons for opposition in more detail. The majority of these arguments against the two techniques reflect those appearing in response to other questions, and there are also a number of responses to question 7 containing similar text and which gives consistent sets of arguments against the techniques.

Ethical arguments

The most common argument given against the two techniques is the involvement of the creation and destruction of embryos, with related concerns about the sanctity of life and interfering with the natural or sacred processes of reproduction. A number of respondents talk about general concerns regarding the slippery slope argument, with others again specifying specific concerns about cloning, designer babies or commodification, and eugenics. A few respondents say that regulation would not necessarily prevent a descent along the slippery slope. Others say that the end simply does not justify the means or that there are too many ethical or moral issues to justify taking these techniques forward.

> "Broadly speaking, all the currently proposed techniques involve the instrumentalisation of human life; irreversible changes to the human germ line; destruction and/or manipulation of individual human embryos; radical challenges to our understanding of individual identity."
>
> Organisation, LIFE Charity

Social arguments

The related issues of a third person as a parent or donor (which itself is related to concerns about playing God) and the impact on the child and its identity are again the most common social arguments against MST and PNT. A few respondents add that there are just too many social issues, or that the impact on the donor (including the risk of exploitation) or on family relationships is of concern.

> "The Church of Scotland welcomes the opportunity to comment on these proposed technologies. As indicated above, we are concerned not only about the specifics of these techniques, but also about the general direction in which this will drive society, and also the effective downgrading of the special status of the early human embryo."
>
> Organisation, Church of Scotland

> "It has to be stressed that egg harvesting is not a risk-free procedure. In the process of MST, it is not clear whether the proposals would require the cycle of the donor woman to be timed to coordinate with the cycle of the woman carrying the mitochondrial disease. This would make the whole process fairly precarious in terms of timing. This would once again show how the donor is being used as an object of exploitation."
>
> Organisation, ProLife Alliance

There is also a common argument which arises in a number of responses to question 7: the concern that historical experience shows embryo research has consistently failed to deliver results and that these techniques would therefore be offering false hope to a vulnerable group of people, and/or that mitochondrial disease would not be eradicated.

Risks, alternatives and wider implications

Another very common response to question 7 is that scientists are already working on other techniques for addressing mitochondrial disease and that these should be pursued instead of MST or PNT. As with previous questions, some respondents state that people have no right to a healthy and/or genetically related child, and a number of preferred alternatives are cited; these include use of donor eggs and adoption.

Unintended or unknown future risks, consequences and impacts are again a concern for a number of respondents. This includes the risks of altering the germ line, with some respondents stating that these techniques involve cloning, and others highlighting the unacceptability of altering DNA at all. There are also concerns that, just because a technique is possible, this does not automatically mean it should be used, and that our current scientific understanding here is limited. The role and motivation of scientists is also of concern to a number of respondents.

As with previous questions, concern is expressed that these techniques are not legal anywhere else (and indeed could result in a prison sentence) and that the UK would be the first to cross this boundary. Some respondents say this is not the UK's decision to make without considering worldwide consequences, or that they are concerned regulation would not be consistent should these techniques become widely available.

Finally, other respondents touch on the cost of these techniques; either specifically that they are too expensive to be justified, or more broadly that there are other issues which should be prioritised. There are also comments expressing concern that the techniques would lead to an increase in population.

11.2.2 Arguments for the introduction of the techniques

In response to this question some respondents simply state their support for the techniques or for a change in law, while others outline their reasons for support in more detail. The majority of these arguments in support of the two techniques again reflect those appearing in response to other questions, and are summarised below.

Social arguments

The most common argument in favour of the two techniques in response to question 7 is the degree to which mitochondrial disease causes suffering and affects both sufferers and their families, with many citing personal experience. Related to this are a number of other common responses about the benefits to the health of the child and to potential parents or families, as well as the avoidance or eradication of the disease being a good thing. The potential for these techniques to reduce the overall burden on services, including the NHS, is also mentioned by some respondents.

Ethical arguments

As with previous questions, the imperative to 'help if we can' is the most common ethical argument in favour of MST and PNT. A few respondents state that people have a right to a healthy and/or genetically related child. There are also some more general comments from respondents who have no concerns about the slippery slope specifically, or about ethics more widely, with a couple of comments again favouring MST over PNT because of less involvement of embryos in the former.

Science, progress and comparisons

Again, some respondents talk about the positive aspect of the two techniques either in terms of general scientific progress or their potential to lay the foundations for other new treatments (either for mitochondrial disease or other conditions). A few respondents suggest that the UK could be the leader in these new techniques, that it is natural progress, or that the underlying science should be allowed to progress as far as it can.

In terms of risks and benefits, some respondents explicitly state they are satisfied that the techniques are safe, that the risks are acceptable or that the benefits would outweigh the costs or other considerations. In addition, a few respondents suggest that these techniques would be preferable to other existing options, or simply that there is no reason not to allow them to progress.

> "Objections have been raised against these techniques on the grounds that mitochondrial donation, and germline alterations to DNA, are "unnatural". However, all medical interventions, including transplants, antibiotics, vaccines and even setting of broken bones, are to a greater or lesser extent unnatural. What these procedures, and mitochondrial donation, have in common, is that they offer the potential for humanity to overcome the cruelties of nature, and to offer people affected by disease the chance of a healthier life.
>
> When new medical treatments are given to human beings for the first time, it is never possible to be certain that these will be 100 per cent safe or effective. Even the most exhaustive research can establish only that a technique is sufficiently likely to be safe to justify first-in-man clinical use in a research setting. If medicine is to progress, however, doctors must be permitted to use new techniques when evidence suggests these are

indeed sufficiently safe and effective to use on patients for the first time. In the case of mitochondrial donation, there will be much more evidence for safety and effectiveness available before the first clinical use than was available for many other techniques, such as organ transplants and IVF."

Organisation, Wellcome Trust

11.2.3 Other considerations

Aside from those respondents who do not give any response to question 7, a number explicitly state there are no further considerations beyond what they have already said, while a few say they do not know. Some respondents compare the considerations for mitochondria replacement to those for other existing treatments or techniques, for example IVF. Other considerations and wider issues raised by respondents are summarised here and in section 11.2.4.

Ethical and social considerations

A number of ethical and social considerations appear in response to question 7, all of which have also appeared in response to previous questions. The most common ethical considerations in response to this question are around consideration of the slippery slope argument (including comments that these techniques are different from those which would be required for cloning or designer babies) and equity of provision. The most common social considerations in response to this question include consideration of overall societal impact, impacts on future generations, the number of people for whom the techniques would be relevant, and the effect these techniques might have on society's attitudes towards disabled people in general or sufferers of mitochondrial disease in particular.

Regulation, criteria and practicalities for application

Several respondents discuss regulation in response to this question. Other than saying it is needed (although there is one respondent who says this kind of research should not be subject to government regulation), there are a number of specific suggestions for regulation. These include the role of the regulator in limiting the application of the techniques and ensuring practitioners do not overstep certain boundaries, as well as other roles such as building in a review process (e.g. for newly classified diseases), prescribing the list of diseases, balancing control with flexibility, regulating clinics and physicians, ensuring provision of counselling, and providing guidelines or a code of practice.

"If these techniques are introduced, we wish to see protection and promotion of the autonomy of the various parties that may be affected. This may require additional stipulations beyond current safeguards on matters such as counselling and information for couples and donors. At present, those seeking licensed assisted reproduction treatments in the UK are offered, under the HFEA act, "proper" information and a "suitable opportunity to receive proper counselling about the implications" of the treatment. If introduced, the provision of cell reconstruction treatments should follow this model. Furthermore, given the complex nature of mitochondrial inheritance and the issues of novelty around reconstructing embryos, we suggest that while the initial discussions about the procedure could be within a routine setting, there should be further opportunity offered for prospective parents to speak to a specialist with appropriate training and up to date information in a dedicated unit accustomed to dealing with mitochondrial disorders (paragraphs 5.9-5.10).

We believe that in the first instance that PNT and MST (or any comparable future treatment) should only be offered as part of a research trial in centres specialising in mitochondrial disorders. Consent to follow up would need to be included as a mandatory part of parental consent to participating in the trial (paragraph 5.6)…"

Organisation, Nuffield Council on Bioethics

A few respondents talk specifically about international regulation, for example concerns that if the UK does not take these techniques forward then other countries with less rigorous controls in place may do so and that UK patients may go abroad for treatment, or that it might be difficult to follow up patients coming from abroad to receive treatment in the UK.

As with question 6, some respondents suggest a number of criteria for deciding whether to progress a specific technique, to help choose between them or to help decide on which cases they should be used for. Safety and success rate/efficacy/efficiency of the technique are again the most commonly mentioned criteria, with the addition of seriousness of disease or risk to the child, cost or value, medical evidence or advice, family situation or ability to provide, patient need or appropriateness, and others. The parents or the parents and clinician together, and the regulator, are again mentioned as potential decision makers for who is eligible and for which technique. Others mention the need for a national screening programme to determine eligibility for treatment.

> "How do we know whether or not we have mitochondrial disease? There needs to be a national screening programme. My family only found out that this disease existed, and that others in the family are at risk, after losing a family member to it. Screening in pregnancy should be mandatory in order to eradicate this disease."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

In terms of practicalities, the question of who would pay for the treatments is raised by a number of respondents, some of whom say explicitly that the NHS should or should not fund treatment. The need to explore the question of commercial benefits to clinics in offering these techniques is also mentioned by a few respondents. The requirement for patients to receive a good level of information and involvement in the decision, as well as the availability of support and counselling, is a common suggestion. In addition, a small number of respondents discuss donor considerations, such as recruiting and screening donors, storing records of donations and whether or not to pay donors.

Science, further research and monitoring

A number of respondents discuss the need either for further research, trials or evidence if or as the techniques progress further, or for follow-up studies and monitoring of patients who undergo the procedure/s. There are also some more disparate comments about science in general or in relation to this particular decision.

> "Our economy could benefit from a stronger more proactive scientific and technological sector. This could benefit everyone - present and future."
>
> Individual, Other

> "The more information which comes to light about the physical and emotional outcomes from all forms of assisted reproduction, the more it becomes apparent that it is a branch of medicine which seriously conflicts with the Hippocratic oath: "First do no harm". Scientists are proposing a new and convoluted form of IVF procedure when finally, after 30 years, emerging studies are showing what some of us have worked out for ourselves, despite regular denials from the industry, that babies born through standard IVF are 25% more likely to have birth defects. The use of IVF, with or without the use of donor gametes, should be discouraged."
>
> Individual, Personal experience of egg, sperm or embryo donation or donor conception

> "Decision makers should consider that they will have significant power to influence the course of science in this field.
>
> If allowed, we should make all effort to succeed in the trials (while not obscuring good science) as a simple lack of diligence can cause the door to shut on all therapies of this kind."
>
> Individual, Student, Researcher

Others mull on the motivations of scientists and the progress made so far, as highlighted by the range of comments below:

> "The drive to research these problems that a handful of members of our society face is caring. The possibility that dark forces are at work attempting to subvert society should be rejected as the silly work of over active imaginations."
>
> Individual, Other

> "Those in the medical profession must be humble and seeking the benefit of patients and not personal glory."
>
> Individual, Other

> "I think that the decision makers should take into account that this is not a cure in the traditional sense but should be viewed as preventative medicine at its most advanced."
>
> Individual, Family member/friend of someone affected by mitochondrial disease, Other

Other considerations and references

A small number of respondents reflect back on previous responses about donation status and the nature of information received by the child who is produced as a result of this treatment. Others discuss scientific aspects of the techniques, for example: the nature of mitochondria and mitochondrial DNA; other procedures; and the variety of forms of mitochondrial disease.

Similar to responses to previous questions, many respondents make reference to the views of other people generally or other specific individuals and groups, religious views, government and the HFEA. Others comment on the role of the media, either in reference to specific coverage of this issue they have seen or heard, or to the way the issue tends to be framed. The need for a clear, neutral coverage of the facts is suggested by some; and there is also the suggestion from a few respondents that reporting of the techniques so far has been misleading in one way or another:

> "The decision makers must consider the significant benefit to the lives of the parents and the child that avoid mitochondrial diseases whilst rising above the sloppy journalism citing 3 parents. The techniques being discussed here DO NOT create 3 parents..."
>
> Individual, Other

Other respondents cite relevant research, documents or websites in support of their responses, as with responses to other questions.

11.2.4 Context and decision making

Making the decision

As well as some questions about who will be making the decision and on what grounds, there are a number of comments on the nature of overall decision to be made in response to question 7, with some respondents recognising that this is a complex decision covering new or difficult territory. Others call for rational and objective consideration of the issue, the need to weigh up the overall risks with benefits or net gain, and the need to humanise the issue away from "cold ethical debate". On a similar note, the question of whether science or ethics should be central to the decision making process is raised by some respondents:

> "The ethical questions should take precedence over the scientific considerations."
>
> Individual, Other

> "I hope that the decision will be taken on consequentialist grounds, following the consensus of the scientific community."
>
> Individual, Other

The speed of implementation, should a decision to proceed be made, also elicits varied views from those few respondents who comment on it, with some calling for a speedy progression and others for caution:

> "It is not urgent in the scheme of things to proceed now, there are many benefits from waiting."
>
> Individual, Other

> "It would be a shame to see one such as this, which has so many benefits andrew [sic] if any drawbacks, not be put into effect as soon as possible."
>
> Individual, Other

Taking into account specific views

Primarily in support of their views in support of or opposition to the two mitochondria replacement techniques, a number of respondents suggest that decision makers should talk to or take into account the views of particular groups or people, or that undue weight should not be given to particular views. Illustrating a similar tension as the science/ethics question outlined above, some respondents would like the views of different religious groups or of people with firsthand experience of mitochondrial disease to be specifically listened to; some are also concerned that vocal objections, for example based on ethics or religion, should not overshadow the views or needs of those who would benefit from these treatments.

Examples of specific viewpoints some respondents would like decision makers to take into account:

> "The decision makers should talk to people who actually suffer from mitochondrial disease. So little is known about it that even when you talk to some doctors about it, they have never heard of it. The people who make the decision cannot make a proper decision without knowing all the facts, it is a rare disorder most people haven't got a clue what it does to you and how it makes you feel, they need to know."
>
> Individual, Personally affected by mitochondrial disease

> “People who know more about the treatments should visit people with different religious views and they should take note on their views. The older generations should be questioned too.”
>
> Individual, Student

> “I think that if everyone was made to talk to and interact with parents of disabled children they will find out a lot more than just thinking they know from seeing it from a distance.”
>
> Individual, Other

> “The views of the wider population should be considered and upheld at all times.”
>
> Individual, Other

> “I would want consultation with disabled people and stakeholders to ask what they think of this as well - not just 'normal' people who see disability as a terrible dark thing to be avoided.”
>
> Individual, Personally affected by mitochondrial disease, Family member/friend of someone affected by mitochondrial disease

Examples of specific viewpoints some respondents would like decision makers not to give undue weight to:

> “Many people will have philosophical objections to these procedures; based on abstract ideas of what it means to be human, religious concerns about 'playing god', worries about what may possibly lie in the future if we take a step in this direction. While these are all relevant considerations, and issues for society to discuss honestly, these concerns of the majority should not be given undue weight against the real needs of the minority who actually suffer from this disease, those who will suffer the consequences of a decision to deny this treatment. Similar issues surround the introduction of other medical advancements, from medicines to transplants, but the health and quality of life of the vulnerable and the individual is more important than the abstract concerns of others - the same approach should be taken here.”
>
> Individual, Other

> “If individual families have objections they will not have the treatment. Those who object should not be allowed to deny access to others who could benefit.”
>
> Individual, Other

Other observations:

> “I believe that there is a high correlation between those who do not approve of Mitochondrial Replacement [sic] and those who do not understand either the science behind it or the impact of Mitochondrial Disease upon individuals and their families.
>
> Interestingly, a handful of people commenting on this topic on the BBC website today revealed that they themselves suffered from genetic disorders, including Mitochondrial Disease.

> Perhaps surprisingly, all but one stated that they were very much in favour of Mitochondrial Replacement with only one commenting that they found the idea of eradicating genetic disorders to be personally insulting to them."
>
> Individual, Family member/friend of someone affected by mitochondrial disease

Wider issues and other priorities

Aside from those respondents who focus on other issues or alternatives as part of their opposition to the two techniques, there are also some more neutral comments about wider issues which would be useful topics for further debate or consultation, as well as other societal priorities which respondents feel might be worth looking at either alongside or in preference to mitochondria replacement.

The wider issues mentioned as potential topics for further consultation are fertility treatments, genetic disease more generally, pre-implantation techniques and the use of animals in research. Other priorities suggested as being worth consideration are other health or research priorities more generally, the concept of family, mitochondrial disease diagnosis and/or other treatment avenues, poverty, and psychological or psychiatric care.

The consultation process

Several respondents comment on the consultation process in response to this question. Whilst some say they welcome the consultation and the chance to input or provide other positive comment, others question the neutrality of the consultation or provide other negative comments (for example about poor publicity, bad timing, cost or lack of information). There are also a few specific comments and suggestions about the questions and response form.

> "This consultation is extremely premature, since the experiments on safety are years away from being completed. A 10 week consultation period accompanied by as little overall public discussion as other HFEA consultations usually attract is radically inadequate to dealing with the seriousness of the issues posed by human germ line modification."
>
> Organisation, Human Genetics Alert

Finally, there are a number of comments about follow-up to the consultation. Aside from requests for specific information, these primarily focus on the need for further communication and public education about mitochondria replacement and surrounding issues, including comments on the need for wider debate of the issue (for example utilising more social media) and the ongoing role for the media.

> "There needs to be very clear explanations of the technique itself and explanations of the role of mitochondrial DNA made available to the press to help to combat sensationalist reporting. Examples of the significant value of the technique to families carrying mitochondral deseases [sic] which can be dealt with by the technique also should be well publicised."
>
> Individual, Other

Appendix

A.1 Consultation questions

1. Permissibility of new techniques

Having read the information on this website about the two mitochondria replacement techniques – maternal spindle transfer and pro-nuclear transfer, what are your views on offering (one or both of) these techniques to people at risk of passing on mitochondrial disease to their child? You may wish to address the two techniques separately.

2. Changing the germ line

Do you think there are social and ethical implications to changing the germ line in the way the techniques do? If so, what are they?

3. Implications for identity

Considering the possible impact of mitochondria replacement on a person's sense of identity, do you think there are social and ethical implications? If so, what are they?

4. The status of the mitochondria donor

a) In your view how does the donation of mitochondria compare to existing types of donation? Please specify what you think this means for the status of a mitochondria donor.

b) Thinking about your response to 4a, what information about the mitochondria donor do you think a child should have? (Choose one response only)

- The child should get no information
- The child should be able to get medical and personal information about the mitochondria donor, but never know their identity
- The child should be able to get medical and personal information about the mitochondria donor and be able to contact them once the child reaches the age of 18
- Other
- I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice.

5. Regulation of mitochondria replacement

If the law changed to allow mitochondria replacement to take place in a specialist clinic regulated by the HFEA, how should decisions be made on who can access this treatment? (Choose one response only)

- Clinics and their patients should decide when mitochondria replacement is appropriate in individual cases
- The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and, just for these diseases, permit clinics and patients to decide when it is appropriate in individual cases

- The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and also decide, just for these diseases, when it is appropriate in individual cases
- I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice.

6. Should the law be changed?

In Question 1, we asked for your views on the mitochondria replacement techniques MST and PNT. Please could you now tell us if you think the law should be changed to allow (one or both of) these techniques to be made available to people who are at risk of passing on mitochondrial disease to their child?

7. Further considerations

Are there any other considerations you think decision makers should take into account when deciding whether or not to permit mitochondria replacement?

A.2 Responding organisations

List of responding organisations
Affinity
Alliance for Humane Biotechnology
AMRC and Genetic Alliance UK
Anscombe Bioethics Centre
Association of Clinical Embryologists (ACE) Executive Committee
British Federation of Women Graduates - Northern Region
British Fertility Society
British Heart Foundation
British Medical Association
Cardiff Sixth Form College
CARE
Cathedral School Llandaff
Catholic Parliamentary Office
Centre for Genetics and Society
Christian Concern
Christian Concern & The Christian Legal Centre
Christian Medical Fellowship
Church of England: Mission and Public Affairs Council
Church of Scotland
Clinical Ethics Committee, University Hospitals of Leicester NHS
Comment on Reproductive Ethics (CORE)
Cornwall's Community Standards Association
East Hampshire District Councillor
Escher Fund for Autism
Fareham Community Church
Free Church of Scotland
Friends of the Earth United States and Friends of the Earth England, Wales and Northern Ireland
Galway for life
HEAL UoS (Health Ethics and Law, University of Southampton).
Horsley Evangelical Church
Howell's School Llandaff
Human Genetics Alert

List of responding organisations
Humanist Society Scotland
International Center for Technology Assessment
Islamic Medical Association/UK and on behalf of the Society of Muslim scholars
Justice et Solidarite Mondiales
LIFE Charity
Morality Forum
Muscular Dystrophy Campaign
National Council of Women
National Gamete Donation Trust
Newcastle University
No Less Human
North East Scotland Youth For Christ
Nuffield Council on Bioethics
Our Bodies Ourselves
Porter Dodson Solicitors &Advisors
Pro Life Alliance
Pro-Choice Alliance for Responsible Research
PROGAR
Progress Educational Trust
ProLife Alliance
RedBridge People First
Resident Community of Pilgrims Hall Christian Centre
Retired
Right To Life
Royal College of Obstetricians and Gynaecologists
Royal College of Physicians
Scottish Council on Human Bioethics
Scottish Council on Human Bioethics
Society for the Protection of Unborn Children
Spring Road Evangelical Church
St Bernadette's Catholic Church, Larbert, Stirlingshire
The Academy of Medical Sciences
The Christian Institute

List of responding organisations
The Lily Foundation
Trinity Grace Church, Ramsbottom
University Hospitals of Leicester NHS Trust (Clinical Ethics Committee)
Wellcome Trust
Women and Medical Technologies

A.3 Analysis: List of themes

Theme	Acronym
Acceptability	AC
Arguments against	AG
Arguments in favour	FA
Considerations	CO
Consultation process	CP
Decision making	DM
Donation status	DS
Information	IN
Legal Status	LS
Other	O
References	RF
Science	SC
Social and ethical	SE

A.4 Analysis: List of codes applied per question

The tables below list the themes and codes applied to the text of responses to each question of the consultation and the number of times that each code was used.

1. Permissibility of new techniques

Having read the information on this website about the two mitochondria replacement techniques – maternal spindle transfer and pro-nuclear transfer, what are your views on offering (one or both of) these techniques to people at risk of passing on mitochondrial disease to their child? You may wish to address the two techniques separately.

Code	Count
AC - Acceptable - MST	20
AC - Acceptable - MST and PNT/general	349
AC - Acceptable with caveat - MST	3
AC - Acceptable with caveat - MST and PNT/general	106
AC - Acceptable with caveat - PNT	3
AC - Not acceptable - MST	2
AC - Not acceptable - MST and PNT/general	502
AC - Not acceptable - PNT	24
AC - Not sure - MST and PNT/general	3
AC - Not sure - PNT	2
AC - Overall - not for me to decide	4
AC - Overall - unable/not qualified to answer	5
AC - Overall - understand issue/have sympathy	32
AC - Overall - unsure/no strong view	4
AC - Preference - MST over PNT	72
AC - Preference - no preference	12
AC - Preference - PNT over MST	11
AG - Altering DNA - cloning/hybridisation	46
AG - Altering DNA - impact on germ line/lineage	109
AG - Altering DNA - not acceptable	41
AG - Costs/risks - outweigh benefits	42
AG - Disease - will not be eradicated/not a cure	9
AG - Donation - risk/exploitation	31
AG - Ethics - egg (mainly MST) creation/destruction	22
AG - Ethics - embryo (mainly PNT) creation/destruction	232
AG - Ethics - end does not justify means	23
AG - Ethics - general/too many ethical issues	56

Code	Count
AG - Ethics - interfering with evolution/playing god	70
AG - Ethics - judging value/worth of life (particularly PNT)	13
AG - Ethics - lack of consent/choice	16
AG - Ethics - no right to healthy/genetically related child	20
AG - Ethics - other comment	18
AG - Ethics - sanctity/dignity of human life	101
AG - Ethics - UK first in crossing ethical boundary	21
AG - Future - risks/impacts/unintended consequences	160
AG - MST - could be more emotionally difficult	2
AG - MST & PNT - both involve IVF/embryo destruction	68
AG - PNT - ethically worse	30
AG - PNT - riskier/no guarantee of survival	4
AG - Population - artificially selected/GM	7
AG - Population - too big/would increase	4
AG - Preferable alternative - adoption	26
AG - Preferable alternative - counselling/support	1
AG - Preferable alternative - decide not to conceive	10
AG - Preferable alternative - donor eggs	12
AG - Preferable alternative - education	1
AG - Preferable alternative - other treatment/cure of MD	79
AG - Preferable alternative - other/general	19
AG - Preferable alternative - screening eggs/embryos	5
AG - Regulation - may not be consistent across the board	1
AG - Science - false hope/may not work	24
AG - Science - just because it is possible does not mean it should be done	13
AG - Science - role/motivation of scientists	10
AG - Science - understanding is limited	33
AG - Slippery slope - attitudes to euthanasia	2
AG - Slippery slope - cloning	35
AG - Slippery slope - concerns	34
AG - Slippery slope - designer babies/commoditisation	71
AG - Slippery slope - eugenics	49
AG - Social - general/too many social issues	6
AG - Social - hardship is natural/contributes to strength of society	3
AG - Social - impact on child/identity/psychology	85

Code	Count
AG - Social - impact on donor/donor considerations	14
AG - Social - impact on family relationships	13
AG - Social - impact on parents	8
AG - Social - legal implications/scenarios	7
AG - Social - other comment	7
AG - Social - prioritise other issues/solutions	10
AG - Social - third person as parent/donor	129
AG - Social - worth of MD sufferers/disabled people	17
AG - Wider issue - against artificial fertilisation	10
CO - Alternatives - encourage/make adoption easier	3
CO - Alternatives - other comment	9
CO - Availability - NHS cover	4
CO - Availability - NHS should not cover/fund privately	5
CO - Business interest/involvement	4
CO - Cost/funding - general/who pays	11
CO - Criteria - cost/value	12
CO - Criteria - medical evidence/advice	16
CO - Criteria - other	6
CO - Criteria - parent/patient choice	30
CO - Criteria - patient need/appropriateness	17
CO - Criteria - safety	57
CO - Criteria - success rate/efficacy/efficiency	66
CO - Donation - availability/origin	2
CO - Donation - like organ/blood	1
CO - Donation - like sperm/egg/IVF	4
CO - Donor status - record identity	3
CO - Donor status - rights/responsibilities	8
CO - Embryo or egg rights/life - concern	23
CO - Embryo or egg rights/life - general/other	26
CO - Embryo or egg rights/life - not a concern	10
CO - Ethics - different to designer embryos/cloning	11
CO - Ethics - interfering with evolution/playing god	3
CO - Ethics - lack of consent/choice	4
CO - Ethics - other comment	20
CO - Ethics - where to draw the line with screening/modification	8

Code	Count
CO - Identity - child access to information	5
CO - Identity - child should know about conception	2
CO - Identity - concerns	6
CO - Identity - no concerns	2
CO - Labelling of techniques - misleading/misunderstood	6
CO - MST - could be more publically/ethically acceptable	27
CO - MST - other consideration	4
CO - MST & PNT - other comparative comment	11
CO - MST & PNT - see no/little difference	20
CO - Patients - follow up studies/monitoring	5
CO - Patients - information provision/involvement	25
CO - Patients - may go elsewhere/abroad	1
CO - Patients - rights/responsibilities	1
CO - Patients - support/counselling	1
CO - PNT - other consideration	5
CO - PNT - potentially controversial	10
CO - PNT - use of spare embryos	5
CO - Population - could increase	1
CO - Regulation - limitation of use	3
CO - Regulation - needed	18
CO - Regulation - other comment	5
CO - Regulation - would prevent slippery slope	7
CO - Safety - evidence insufficient	14
CO - Safety - risks is always present with medical procedures	6
CO - Safety - risks vs benefits	14
CO - Science - alternative/additional suggestion	5
CO - Science - further research/trials/evidence	56
CO - Science - mitochondrial function	12
CO - Science - other comment	19
CO - Science - participant understanding	12
CO - Science - should prevail	10
CO - Slippery slope - designer babies/commoditisation	14
CO - Slippery slope - eugenics	1
CO - Slippery slope - general	9
CO - Social - child emotional/psychological impact	7

Code	Count
CO - Social - impact on future generations	4
CO - Social - insurance considerations	2
CO - Social - legal considerations	14
CO - Social - number of cases	14
CO - Social - parents should not be pressurised	6
CO - Social - risk losing valuable individuals	2
CO - Social - third person as parent/donor	10
CO - Social - worth of MD sufferers/disabled people	2
CP - Consultation - challenge information/data	4
CP - Consultation - comment on question	5
CP - Consultation - lack of information	4
CP - Consultation - outcomes	1
CP - Consultation - participants not qualified	2
CP - Consultation - question motivations/bias	4
CP - Consultation - specific information	3
CP - Follow-up - further consultation	6
CP - Follow-up - further info on specific topic/s	1
CP - Follow-up - further info would help form opinion	6
CP - Follow-up - please keep informed	1
CP - Follow-up - public communication/education	2
CP - Website - difficulty	1
CP - Website - general	8
CP - Website - lack of information	2
CP - Website - positive comment	1
CP - Website - video	3
FA - Benefits - outweigh cost/other considerations	25
FA - Cost - no concerns	1
FA - Disease - avoidance important/positive	69
FA - Disease - eradicate	35
FA - Disease - impact on families/sufferers	15
FA - Disease - risks of passing on	11
FA - Disease - scale of suffering underestimated	3
FA - Donation - like organ/blood	8
FA - Donation - like sperm/egg/IVF	2
FA - Ethics - ethical imperative to intervene	30

Code	Count
FA - Ethics - no concerns	40
FA - Ethics - right to healthy/genetically related child	25
FA - Identity - compare to sperm/egg donation	3
FA - Identity - no concerns	10
FA - MST - destroying eggs no concern	10
FA - MST - does not destroy embryos	35
FA - MST - fewer ethical concerns	10
FA - MST - less wastage of genetic material/does not involve father	2
FA - MST - like organ donation	2
FA - MST - might be easier/more efficient	7
FA - MST - other comment in favour	5
FA - MST and PNT - better/alternative to current options	11
FA - MST and PNT - not different from existing practices	7
FA - PNT - fewer ethical concerns	2
FA - PNT - involves the father/normal inheritance better	4
FA - PNT - less risky	2
FA - PNT - more robust/better success rate/economic sense	6
FA - PNT/general - similar to IVF/donation ethically	8
FA - Safety - techniques are safe/risks acceptable	3
FA - Science - could lead to new treatments (MD or other diseases)	4
FA - Science - important/positive	30
FA - Science - natural progress	8
FA - Science - no concerns	3
FA - Science - no genetic traits are passed on	10
FA - Science - nuclear DNA not altered	7
FA - Science - origin of mitochondria/not human	3
FA - Science - other comment	5
FA - Science - UK as a leader in new techniques	3
FA - Slippery slope - not a concern	21
FA - Social - benefits to potential parents/families	80
FA - Social - general benefit to society/public health	13
FA - Social - genetic parentage/no third parent issues	11
FA - Social - health/wellbeing of the child	97
FA - Social - poor provision of care for sufferers	1
FA - Social - reduces burden on services/NHS	4

Code	Count
O - Blank response/no comment	2
O - Refer to other question	6
RF - Culture/literature	2
RF - Current legislation	20
RF - Current legislation - non UK	36
RF - External document	6
RF - External event/discussion	2
RF - HFEA	14
RF - Historical experience	14
RF - Media coverage	3
RF - Participant - friend/relative/child with MD/similar disease	40
RF - Participant - has MD/similar disease	20
RF - Participant - info about	51
RF - Participant - other medical details	12
RF - Participant - personal details	4
RF - Politics/government	19
RF - Relevant research	14
RF - Religion	43
RF - Scientific review panel	3
RF - Specific individual/organisation/group	8
RF - Views of other people/participants	30

2. Changing the germ line

Do you think there are social and ethical implications to changing the germ line in the way the techniques do? If so, what are they?

Code	Count
AC - Acceptable - MST and PNT/general	1
AC - Not acceptable - MST and PNT/general	4
AC - Overall - unsure/no strong view	1
CP - Consultation - challenge information/data	2
CP - Consultation - comment on question	3
CP - Consultation - lack of information	1
CP - Consultation - other comment	1
CP - Consultation - other positive comment	1
CP - Consultation - participants not qualified	2
CP - Consultation - question motivations/bias	2

Code	Count
CP - Consultation - specific information	1
CP - Consultation - welcomed	2
CP - Follow-up - further consultation	7
CP - Follow-up - further info on specific topic/s	2
CP - Follow-up - other comments	1
CP - Follow-up - public communication/education	9
CP - Website - video	2
O - Blank response/no comment	3
O - Other/general comment	2
O - Refer to other question	34
RF - Current legislation	5
RF - Current legislation - non UK	55
RF - External document	2
RF - External website	4
RF - HFEA	7
RF - HFEA - website	3
RF - Historical experience	19
RF - Media coverage	3
RF - Other evidence/examples	3
RF - Participant - friend/relative/child with MD/similar disease	9
RF - Participant - has MD/similar disease	6
RF - Participant - info about	11
RF - Participant - other medical details	4
RF - Participant - personal details	1
RF - Politics/government	6
RF - Relevant research	6
RF - Religion	40
RF - Specific individual/organisation/group	10
RF - Views of other people/participants	50
SC - DNA - mutates anyway over time	7
SC - DNA - natural mixing	7
SC - DNA - nuclear DNA/genome not affected	39
SC - DNA - other comment	5
SC - Germ line - could reduce in diversity	4
SC - Germ line - diversity/mixing is beneficial/genetic advantage	4

Code	Count
SC - Germ line - not significantly changed	7
SC - Germ line - ok to alter	22
SC - Germ line - other comment	39
SC - Germ line - should not be altered	22
SC - Germ line - will be repaired/not enhanced	5
SC - Mitochondria - function/form	18
SC - Mt DNA - does not determine identity/traits	38
SC - Mt DNA - keep faulty DNA for posterity	2
SC - Mt DNA - maternal/female line	19
SC - Mt DNA - may affect identity/traits	10
SC - Mt DNA - origin/not human	3
SC - Mt DNA - other comment	24
SC - Mt DNA - quantity/impact too much	2
SC - Mt DNA - small quantity/impact	30
SC - Mt DNA - suggested source for donation	7
SC - Other procedures - abortion/termination	5
SC - Other procedures - adoption	16
SC - Other procedures - genetic techniques/gene therapy	6
SC - Other procedures - IVF/egg or sperm donation/surrogacy	46
SC - Other procedures - not conceiving	4
SC - Other procedures - organ/tissue/blood donation	21
SC - Other procedures - other/general	5
SC - Other procedures - stem cell donation	4
SC - Other procedures - vaccination	4
SC - Overall - addition/alternative suggestions	3
SC - Overall - balancing science/ethics/religion/society	5
SC - Overall - further research/trials/evidence	14
SC - Overall - invest in other priorities/solutions	18
SC - Overall - motivation of scientists	5
SC - Overall - nature of medicine/science	17
SC - Overall - object to infertility treatment	4
SC - Overall - one-off/single generation treatment	3
SC - Overall - other comment	21
SC - Overall - restricting to male births	4
SC - Overall - trust/mistrust of scientists	18

Code	Count
SC - Overall - understanding is limited	19
SC - Progress - has gone too far to stop now	2
SC - Progress - natural consequence/function of humanity	10
SC - Progress - other comment	5
SC - Progress - possibility does not mean it should happen automatically	6
SC - Progress - reducing MD is good/positive	91
SC - Progress - requires caution	6
SC - Regulation - can't guarantee limits	1
SC - Regulation - international considerations	6
SC - Regulation - needed	10
SC - Regulation - other comment	8
SC - Regulation - specifics	3
SC - Regulation - would prevent slippery slope	4
SC - Safety - other comment	13
SE - Ethical - benefits small number	4
SE - Ethical - consent/choice concern	38
SE - Ethical - consent/choice no concern	4
SE - Ethical - consent/choice other	8
SE - Ethical - embryo rights/usage concern	158
SE - Ethical - embryo rights/usage no concern	4
SE - Ethical - embryo rights/usage other	16
SE - Ethical - end does not justify means	2
SE - Ethical - equity of provision	6
SE - Ethical - ethical imperative to intervene	39
SE - Ethical - genetic modification of human embryos	10
SE - Ethical - implications	8
SE - Ethical - implications minimal/insignificant	1
SE - Ethical - interfering with evolution/playing god	73
SE - Ethical - interfering/playing god already happens	17
SE - Ethical - interfering/playing god is ok	8
SE - Ethical - judging value/worth of life	3
SE - Ethical - limitation of use	13
SE - Ethical - no implications/concerns	29
SE - Ethical - no right to healthy/genetically related child	10
SE - Ethical - no slippery slope/not crossing boundary	29

Code	Count
SE - Ethical - not genetic modification	2
SE - Ethical - other comment	15
SE - Ethical - right to healthy/genetically related child	4
SE - Ethical - sanctity/dignity of human life	67
SE - Ethical - slippery slope generally/crossing boundary	141
SE - Ethical - slippery slope other comment	30
SE - Ethical - slippery slope to designer babies/commoditisation	150
SE - Ethical - slippery slope to eugenics	70
SE - Ethical - slippery slope/similar to cloning	72
SE - Ethical - UK first in crossing ethical boundary	4
SE - Ethical tradeoffs - MST vs PNT	7
SE - Ethical tradeoffs - society vs individual	1
SE - General - benefits outweigh issues	68
SE - General - comment on MST specifically	6
SE - General - comment on PNT specifically	14
SE - General - current social/ethical expectations	4
SE - General - implications (Yes)	301
SE - General - implications all/largely positive	10
SE - General - implications based on personal beliefs	8
SE - General - implications minimal/insignificant	13
SE - General - issues outweigh benefits	8
SE - General - no different to current breeding habits	5
SE - General - no implications/concerns (No)	158
SE - General - not sure	2
SE - General - other comment on implications	27
SE - General - other procedures acceptable/better	12
SE - General - preferable to other procedures	12
SE - General - similar to other procedures	29
SE - General - unforeseen problems/impacts/health issues	232
SE - Social - attitudes towards disabled people/MD sufferers	53
SE - Social - attitudes towards those not treated/and their parents	27
SE - Social - attitudes towards those treated	56
SE - Social - availability of counselling/testing/support	2
SE - Social - benefit to future generations	30
SE - Social - benefits to potential parents/families/relationships	25

Code	Count
SE - Social - child awareness not necessary	1
SE - Social - child awareness/understanding	19
SE - Social - child emotional/psychological impact	74
SE - Social - child health/wellbeing improved	59
SE - Social - child health/wellbeing other	7
SE - Social - child ID/mixed genetic make-up	87
SE - Social - child impacts/damage (other/general)	30
SE - Social - child rights	22
SE - Social - cost/resources	6
SE - Social - donor considerations	31
SE - Social - hardship is natural/contributes to strength of society	3
SE - Social - impact on family relationships (not third parent)	24
SE - Social - impact on future generations	175
SE - Social - impact on lineage/traceability	30
SE - Social - implications	4
SE - Social - implications all/largely positive	1
SE - Social - implications minimal/insignificant	3
SE - Social - implications subjective/time-bound	2
SE - Social - increased burden on NHS	5
SE - Social - issues from having MD/disability	7
SE - Social - legal implications/issues	17
SE - Social - minimal family/relationship impacts	2
SE - Social - no ID issues/implications foreseen	7
SE - Social - no implications/concerns	12
SE - Social - no lineage/traceability concerns	2
SE - Social - no third party parentage issues	11
SE - Social - not sure	2
SE - Social - ongoing monitoring/follow-up	29
SE - Social - overall societal benefit/not harmful	11
SE - Social - overall societal impact	10
SE - Social - overpopulation	9
SE - Social - parent awareness/understanding	4
SE - Social - parent psychological impact	10
SE - Social - parent rights/responsibilities	14
SE - Social - parents should not be pressurised	16

Code	Count
SE - Social - public/societal response/fear	17
SE - Social - reduced burden on services/NHS	11
SE - Social - risk losing valuable individuals	7
SE - Social - third party parentage issues	119

3. Implications for identity

Considering the possible impact of mitochondria replacement on a person's sense of identity, do you think there are social and ethical implications? If so, what are they?

Code	Count
AC - Not acceptable - MST and PNT/general	11
CO - Criteria - parent/patient choice	2
CO - Labelling of techniques - misleading/misunderstood	7
CO - Patients - information provision/involvement	5
CP - Consultation - comment on question	6
CP - Consultation - comment on response form	1
CP - Consultation - lack of information	1
CP - Consultation - question motivations/bias	2
CP - Consultation - specific information	2
CP - Follow-up - public communication/education	8
CP - Website - general	1
CP - Website - video	4
DS - Donor - responsibility for actions/know what they are getting into	2
DS - Donor function - providing medical solution/repair	10
DS - Donor motivation - other	1
DS - Donor status - is not parent/relation to child	7
DS - Donor status - is parent/relation to child	4
DS - Donor status - is unclear/ambiguous	4
DS - Donor status - no rights/responsibilities to child	4
IN - Age - other comment	1
IN - Child identity - should not be known by donor	1
IN - Child rights - no right/reason to access any information	2
IN - Child rights - to information generally	2
IN - Child rights - to know origins/donor/parents	36
IN - Donor identity - not relevant/necessary	3
IN - Donor identity - other comment	8
IN - Donor identity - should be available (general)	4

Code	Count
IN - Donor identity - should be optional/not mandatory	1
IN - Donor rights - to anonymity/lack of intrusion	1
IN - Donor status - same as blood/tissue/organ donor	7
IN - Donor status - same as egg/sperm donor	2
IN - Logistics - database/infrastructure resourcing	1
IN - Medical info - available for specific reasons/circumstances	1
IN - Medical info - should be available (general)	6
IN - Overall - depends on MtDNA function	1
IN - Overall - other comment	1
IN - Overall decision - flexible/mutual/depends	1
O - potential quote	1
O - Refer to other question	42
RF - Current legislation	1
RF - Current legislation - non UK	6
RF - External document	2
RF - HFEA	5
RF - Historical experience	14
RF - Media coverage	6
RF - Other evidence/examples	8
RF - Participant - friend/relative/child with MD/similar disease	5
RF - Participant - has MD/similar disease	3
RF - Participant - info about	23
RF - Participant - other medical details	5
RF - Politics/government	3
RF - Relevant research	5
RF - Religion	13
RF - Specific individual/organisation/group	5
RF - Views of other people/participants	17
SC - DNA - natural mixing	4
SC - DNA - nuclear DNA/genome not affected	36
SC - DNA - other comment	3
SC - Germ line - other comment	2
SC - Germ line - should not be altered	2
SC - Mitochondria - function/form	31
SC - Mt DNA - does not determine identity/traits	97

Code	Count
SC - Mt DNA - limited amount/types	2
SC - Mt DNA - maternal/female line	4
SC - Mt DNA - may affect identity/traits	19
SC - Mt DNA - origin/not human	3
SC - Mt DNA - other comment	9
SC - Mt DNA - small quantity/impact	63
SC - Other procedures - abortion/termination	3
SC - Other procedures - adoption	68
SC - Other procedures - genetic techniques/gene therapy	2
SC - Other procedures - IVF/egg or sperm donation/surrogacy	112
SC - Other procedures - not conceiving	1
SC - Other procedures - organ/tissue/blood donation	75
SC - Other procedures - other/general	4
SC - Other procedures - stem cell donation	1
SC - Other procedures - timing is different	1
SC - Other procedures - vaccination	1
SC - Overall - addition/alternative suggestions	1
SC - Overall - assessing/managing risk	1
SC - Overall - further research/trials/evidence	7
SC - Overall - invest in other priorities/solutions	8
SC - Overall - motivation of scientists	1
SC - Overall - nature of medicine/science	2
SC - Overall - object to infertility treatment	1
SC - Overall - other comment	8
SC - Overall - question about application	2
SC - Overall - trust/mistrust of scientists	6
SC - Overall - understanding is limited	6
SC - Progress - natural consequence/function of humanity	1
SC - Progress - possibility does not mean it should happen automatically	1
SC - Progress - reducing MD is good/positive	12
SC - Regulation - other comment	3
SC - Regulation - specifics	1
SC - Regulation - would prevent slippery slope	1
SC - Safety - other comment	1
SE - Ethical - benefits small number	1

Code	Count
SE - Ethical - consent/choice concern	11
SE - Ethical - consent/choice no concern	4
SE - Ethical - consent/choice other	1
SE - Ethical - embryo rights/usage concern	53
SE - Ethical - end does not justify means	2
SE - Ethical - ethical imperative to intervene	7
SE - Ethical - implications	4
SE - Ethical - interfering with evolution/playing god	37
SE - Ethical - interfering/playing god is ok	3
SE - Ethical - judging value/worth of life	2
SE - Ethical - no implications/concerns	3
SE - Ethical - no right to healthy/genetically related child	3
SE - Ethical - no slippery slope/not crossing boundary	2
SE - Ethical - other comment	5
SE - Ethical - right to healthy/genetically related child	2
SE - Ethical - sanctity/dignity of human life	8
SE - Ethical - slippery slope generally/crossing boundary	22
SE - Ethical - slippery slope to designer babies/commoditisation	11
SE - Ethical - slippery slope to eugenics	7
SE - Ethical - slippery slope/similar to cloning	10
SE - Ethical - UK first in crossing ethical boundary	1
SE - Ethical tradeoffs - health vs identity	18
SE - Ethical tradeoffs - society vs individual	1
SE - General - benefits outweigh issues	53
SE - General - comment on MST specifically	25
SE - General - comment on PNT specifically	35
SE - General - current social/ethical expectations	6
SE - General - implications (Yes)	174
SE - General - implications all/largely positive	1
SE - General - implications based on personal beliefs	2
SE - General - implications cannot be understood	4
SE - General - implications minimal/insignificant	6
SE - General - issues outweigh benefits	3
SE - General - no different to current breeding habits	1
SE - General - no implications/concerns (No)	134

Code	Count
SE - General - not sure	3
SE - General - other comment on implications	7
SE - General - other procedures acceptable/better	1
SE - General - similar to other procedures	11
SE - General - unforeseen problems/impacts/health issues	68
SE - Social - attitudes towards disabled people/MD sufferers	4
SE - Social - attitudes towards those not treated	3
SE - Social - attitudes towards those treated	41
SE - Social - availability of counselling/testing/support	10
SE - Social - benefit to future generations	6
SE - Social - benefits to potential parents/families/relationships	6
SE - Social - child awareness not necessary	2
SE - Social - child awareness/understanding	105
SE - Social - child emotional/psychological impact	228
SE - Social - child health/wellbeing improved	37
SE - Social - child health/wellbeing other	4
SE - Social - child ID/mixed genetic make-up	368
SE - Social - child impacts/damage (other/general)	13
SE - Social - child may want to meet donor	3
SE - Social - child rights (non-information related)	5
SE - Social - cost/resources	2
SE - Social - donor considerations (other)	16
SE - Social - donor/child bond OR lack of bond	39
SE - Social - donor/child relationship difficulties	21
SE - Social - ethnic/historical ID issues	3
SE - Social - everyone has identity issues	4
SE - Social - ID from nature/genes	10
SE - Social - ID from nurture/upbringing/beyond genetics	71
SE - Social - ID is a changing/evolving concept	4
SE - Social - ID is increasing focus for society	2
SE - Social - ID issues (other)	22
SE - Social - ID issues cannot be known yet	17
SE - Social - ID issues depend on donor status	2
SE - Social - ID issues depend on MtDNA function	2
SE - Social - ID issues for matrilineal societies	3

Code	Count
SE - Social - ID issues less than other procedures	42
SE - Social - ID issues moot/not relevant	3
SE - Social - ID issues more than other procedures	15
SE - Social - ID issues possible	27
SE - Social - ID issues similar/no different to other procedures	131
SE - Social - ID will become fluid/clouded/less clear	5
SE - Social - ID/issues complex/different for everyone	25
SE - Social - impact on family relationships (not third parent)	32
SE - Social - impact on future generations	23
SE - Social - impact on lineage/traceability	25
SE - Social - issues from having MD/disability	7
SE - Social - legal implications/issues	20
SE - Social - lineage/traceability other issues	14
SE - Social - minimal/insignificant ID issues	34
SE - Social - no ID issues/implications foreseen	100
SE - Social - no implications/concerns	4
SE - Social - no lineage/traceability concerns	4
SE - Social - no third party parentage issues	26
SE - Social - ongoing monitoring/follow-up	7
SE - Social - overall societal benefit/not harmful	2
SE - Social - overall societal impact	12
SE - Social - parent psychological impact	27
SE - Social - parent rights/responsibilities	49
SE - Social - parents should not be pressurised	1
SE - Social - positive impact on ID/other	23
SE - Social - public/societal response/fear	9
SE - Social - third party parentage issues	232
SE - Social - who should know the details	5

4. The status of the mitochondria donor

a) In your view how does the donation of mitochondria compare to existing types of donation? Please specify what you think this means for the status of a mitochondria donor.

Code	Count
AC - Acceptable - MST	2
AC - Acceptable - MST and PNT/general	10
AC - Acceptable with caveat - MST	1

Code	Count
AC - Not acceptable - MST and PNT/general	47
AC - Not acceptable - PNT	2
AC - Not sure - MST and PNT/general	1
AC - Overall - understand issue/have sympathy	2
CO - Alternatives - other comment	6
CO - Availability - NHS should not cover/fund privately	1
CO - Labelling of techniques - misleading/misunderstood	11
CO - MST and PNT - see no/little difference	2
CO - Patients - information provision/involvement	1
CP - Consultation - challenge information/data	1
CP - Consultation - comment on question	11
CP - Consultation - other comment	3
CP - Consultation - participants not qualified	1
CP - Consultation - question motivations/bias	1
CP - Consultation - specific information	1
CP - Follow-up - further info on specific topic/s	1
CP - Follow-up - public communication/education	1
CP - Website - general	2
CP - Website - video	1
DS - Donor - availability issues/considerations	20
DS - Donor - is important/should be recognised	17
DS - Donor - may have emotional investment/impact	12
DS - Donor - no emotional investment	2
DS - Donor - payment	11
DS - Donor - responsibility for actions/know what they are getting into	22
DS - Donor - risks/exploitation/health considerations	86
DS - Donor function - contributing to life	15
DS - Donor function - not providing reproductive function	5
DS - Donor function - providing medical solution/repair	36
DS - Donor motivation - gift/altruism	32
DS - Donor motivation - other	2
DS - Donor status - does have rights/responsibilities to child	8
DS - Donor status - is clear/unambiguous	3
DS - Donor status - is not parent/relation to child	39
DS - Donor status - is parent/relation to child/partial parent	47

Code	Count
DS - Donor status - is subjective	6
DS - Donor status - is unclear/ambiguous	27
DS - Donor status - legal considerations	31
DS - Donor status - may change/open to review	7
DS - Donor status - no rights/responsibilities to child	37
DS - Donor status - no status	8
DS - Donor status - not primary concern	2
DS - Donor status - other considerations	17
DS - Mitochondria - 'above' blood	10
DS - Mitochondria - 'above' bone marrow	8
DS - Mitochondria - 'above' egg/sperm/embryo	3
DS - Mitochondria - 'above' organ	6
DS - Mitochondria - 'above' tissue	3
DS - Mitochondria - 'below' donation (general)	2
DS - Mitochondria - 'below' egg/sperm/embryo	33
DS - Mitochondria - 'below' face transplant	1
DS - Mitochondria - 'below' organ	4
DS - Mitochondria - 'below' surrogacy	1
DS - Mitochondria - complex/uncomfortable donation	7
DS - Mitochondria - depends on MST/PNT	30
DS - Mitochondria - depends on MtDNA function	5
DS - Mitochondria - depends on sex of child	2
DS - Mitochondria - difference in choice/consent	5
DS - Mitochondria - difference in longevity of impact	16
DS - Mitochondria - difference in method of donation	3
DS - Mitochondria - difference in perception/ethics	2
DS - Mitochondria - difference in timing	8
DS - Mitochondria - difference is third person DNA/genetic information	94
DS - Mitochondria - different to blood	96
DS - Mitochondria - different to bone marrow	27
DS - Mitochondria - different to donation (general)	77
DS - Mitochondria - different to egg/sperm/embryo	121
DS - Mitochondria - different to organ	102
DS - Mitochondria - different to stem cells	1
DS - Mitochondria - different to surrogacy	3

Code	Count
DS - Mitochondria - different to tissue	12
DS - Mitochondria - envelope/carrier/overcoat	3
DS - Mitochondria - less pervasive	2
DS - Mitochondria - minor/uncomplicated donation	3
DS - Mitochondria - mixed comparison	27
DS - Mitochondria - more pervasive	12
DS - Mitochondria - similar to adoption	2
DS - Mitochondria - similar to biopsy	1
DS - Mitochondria - similar to blood	92
DS - Mitochondria - similar to bone marrow	51
DS - Mitochondria - similar to donation (general)	72
DS - Mitochondria - similar to egg/sperm/embryo/IVF	113
DS - Mitochondria - similar to organ	68
DS - Mitochondria - similar to stem cells	4
DS - Mitochondria - similar to surrogacy	5
DS - Mitochondria - similar to tissue	33
DS - Mitochondria - unessential donation	2
DS - Mitochondria - unique type of donation	10
DS - Origin - allow choice	1
DS - Origin - makes no difference	1
DS - Origin - mitochondria bank/anonymous	3
DS - Origin - should be family member/close relative	2
DS - Origin - should be relative/friend	3
DS - Origin - should be same haplogroup	1
DS - Origin - should be unconnected to family	1
DS - Origin - should not be maternal relative	1
DS - Overall - not sure/no view	8
DS - Overall - oppose donation of all/any kind	10
DS - Overall - other comment	7
DS - Overall - support donation of all/any kind	2
DS - Overall - varied views on donation types	6
IN - Age - 18/when reaching adulthood	10
IN - Age - before 18	1
IN - Age - other comment	1
IN - Child identity - should not be known by donor	7

Code	Count
IN - Child rights - no right to contact donor	2
IN - Child rights - other comment	2
IN - Child rights - should take priority	5
IN - Child rights - to information generally	11
IN - Child rights - to know origins/donor/parents	25
IN - Child rights - to understand process/implications	6
IN - Donor identity - available for specific reasons	1
IN - Donor identity - depends on who the donor is	3
IN - Donor identity - not known by parents	1
IN - Donor identity - not relevant/necessary	6
IN - Donor identity - other comment	7
IN - Donor identity - should be available (general)	17
IN - Donor identity - should be optional/not mandatory	27
IN - Donor identity - should not be available (other/general)	26
IN - Donor rights - not to have relationship with child	1
IN - Donor rights - other comment	5
IN - Donor rights - to anonymity/lack of intrusion	22
IN - Donor rights - to know success of treatment	3
IN - Donor rights - to understand procedure	13
IN - Logistics - donor screening	10
IN - Logistics - information storage/records	11
IN - Medical info - available for specific reasons/circumstances	12
IN - Medical info - not relevant/necessary	1
IN - Medical info - should be available (general)	6
IN - Overall - depends on other factor	1
IN - Overall - legal considerations	3
IN - Overall - no information needed	3
IN - Overall - other comment	6
IN - Overall decision - flexible/mutual/depends	3
IN - Overall decision - parents'/family's	4
IN - Personal info - not relevant/necessary	2
IN - Personal info - should be available (general)	1
IN - Personal info - should not be available (other/general)	1
O - Blank response/no comment	17
O - Refer to other question	18

Code	Count
O - Refer to other response	2
RF - Current legislation	4
RF - Current legislation - non UK	4
RF - External document	2
RF - HFEA	3
RF - Historical experience	2
RF - Media coverage	4
RF - Other evidence/examples	2
RF - Participant - friend/relative/child with MD/similar disease	4
RF - Participant - has MD/similar disease	1
RF - Participant - info about	14
RF - Participant - other medical details	1
RF - Politics/government	4
RF - Relevant research	2
RF - Religion	6
RF - Specific individual/organisation/group	5
RF - Views of other people/participants	10
SC - DNA - nuclear DNA/genome not affected	29
SC - DNA - other comment	6
SC - Germ line - should not be altered	1
SC - Mitochondria - function/form	29
SC - Mt DNA - does not determine identity/traits	56
SC - Mt DNA - limited amount/types	5
SC - Mt DNA - may affect identity/traits	10
SC - Mt DNA - origin/not human	2
SC - Mt DNA - other comment	6
SC - Mt DNA - small quantity/impact	64
SC - Other procedures - adoption	2
SC - Other procedures - IVF/egg or sperm donation/surrogacy	5
SC - Overall - addition/alternative suggestions	1
SC - Overall - further research/trials/evidence	3
SC - Overall - invest in other priorities/solutions	11
SC - Overall - motivation of scientists	1
SC - Overall - need more research/don't know enough	7
SC - Overall - object to infertility treatment	4

Code	Count
SC - Overall - question about application	2
SC - Overall - trust/mistrust of scientists	2
SC - Overall - understanding is limited	5
SC - Progress - reducing MD is good/positive	3
SC - Progress - requires caution	1
SC - Regulation - other comment	3
SC - Regulation - specifics	3
SC - Safety - other comment	1
SE - Ethical - comparison with other donations	4
SE - Ethical - consent/choice concern	5
SE - Ethical - embryo rights/usage concern	157
SE - Ethical - embryo rights/usage other	9
SE - Ethical - end does not justify means	1
SE - Ethical - equity of provision	2
SE - Ethical - implications	4
SE - Ethical - interfering with evolution/playing god	22
SE - Ethical - judging value/worth of life	3
SE - Ethical - no implications/concerns	2
SE - Ethical - no right to healthy/genetically related child	3
SE - Ethical - other comment	5
SE - Ethical - right to healthy/genetically related child	1
SE - Ethical - sanctity/dignity of human life	19
SE - Ethical - slippery slope generally/crossing boundary	12
SE - Ethical - slippery slope to designer babies/commoditisation	6
SE - Ethical - slippery slope to eugenics	2
SE - Ethical - slippery slope/similar to cloning	9
SE - General - benefits outweigh issues	3
SE - General - current social/ethical expectations	3
SE - General - implications (Yes)	3
SE - General - implications minimal/insignificant	1
SE - General - other procedures acceptable/better	4
SE - General - preferable to other procedures	4
SE - General - unforeseen problems/impacts/health issues	28
SE - Social - attitudes towards disabled people/MD sufferers	1
SE - Social - attitudes towards those treated	2

Code	Count
SE - Social - availability of counselling/testing/support	1
SE - Social - benefit to future generations	3
SE - Social - benefits to potential parents/families/relationships	5
SE - Social - child emotional/psychological impact	8
SE - Social - child health/wellbeing improved	4
SE - Social - child ID/mixed genetic make-up	24
SE - Social - child rights	1
SE - Social - donor considerations (other)	3
SE - Social - donor/child bond OR lack of bond	12
SE - Social - donor/child relationship difficulties	2
SE - Social - ID from nurture/upbringing/beyond genetics	1
SE - Social - ID issues (other)	2
SE - Social - ID issues cannot be known yet	1
SE - Social - ID/issues complex/different for everyone	2
SE - Social - impact on family relationships (not third parent)	1
SE - Social - impact on future generations	10
SE - Social - impact on lineage/traceability	3
SE - Social - minimal/insignificant ID issues	1
SE - Social - no ID issues/implications foreseen	4
SE - Social - ongoing monitoring/follow-up	3
SE - Social - overpopulation	1
SE - Social - parent psychological impact	1
SE - Social - parent rights/responsibilities	5
SE - Social - risk losing valuable individuals	1
SE - Social - third party parentage issues	13

b) Thinking about your response to 4a, what information about the mitochondria donor do you think a child should have? (Choose one response only)

- The child should get no information
- The child should be able to get medical and personal information about the mitochondria donor, but never know their identity
- The child should be able to get medical and personal information about the mitochondria donor and be able to contact them once the child reaches the age of 18
- Other
- I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice.

Code	Count
AC - Acceptable - MST	1
AC - Acceptable - MST and PNT/general	2
AC - Not acceptable - MST and PNT/general	103
AC - Not acceptable - PNT	1
AC - Not sure - MST and PNT/general	1
AC - Overall - understand issue/have sympathy	6
AC - Overall - unsure/no strong view	2
AG - Altering DNA - cloning/hybridisation	3
AG - Altering DNA - impact on germ line/lineage	13
AG - Altering DNA - not acceptable	7
AG - Cost - too much/cannot be justified	2
AG - Costs/risks - outweigh benefits	7
AG - Disease - will not be eradicated/not a cure	2
AG - Donation - risk/exploitation	5
AG - Ethics - creation/destruction of egg/embryo	84
AG - Ethics - general/too many ethical issues	39
AG - Ethics - interfering with evolution/playing god	30
AG - Ethics - judging value/worth of life (particularly PNT)	2
AG - Ethics - lack of consent/choice	3
AG - Ethics - no right to healthy/genetically related child	6
AG - Ethics - other comment	1
AG - Ethics - sanctity/dignity of human life	27
AG - Ethics - UK first in crossing ethical boundary	2
AG - Future - risks/impacts/unintended consequences	47
AG - MST - could be more emotionally difficult	1
AG - Population - too big/would increase	1
AG - Preferable alternative - adoption	5
AG - Preferable alternative - decide not to conceive	3
AG - Preferable alternative - IVF	1
AG - Preferable alternative - other treatment/cure of MD	29
AG - Preferable alternative - other/general	1
AG - Regulation - can't guarantee limits	1
AG - Regulation - may not be consistent across the board	2
AG - Science - false hope/may not work	2
AG - Science - just because it is possible does not mean it should be done	4

Code	Count
AG - Science - role/motivation of scientists	4
AG - Science - understanding is limited	2
AG - Slippery slope - cloning	6
AG - Slippery slope - concerns	18
AG - Slippery slope - designer babies/commoditisation	5
AG - Slippery slope - eugenics	7
AG - Social - general/too many social issues	1
AG - Social - impact on child/identity/psychology	45
AG - Social - impact on donor/donor considerations	3
AG - Social - impact on family relationships	2
AG - Social - impact on parents	3
AG - Social - legal implications/scenarios	7
AG - Social - prioritise other issues/solutions	5
AG - Social - third person as parent/donor	23
AG - Social - worth of MD sufferers/disabled people	3
AG - Wider issue - against artificial fertilisation	5
CO - Labelling of techniques - misleading/misunderstood	11
CP - Consultation - comment on question	30
CP - Consultation - cost concern	1
CP - Consultation - other negative comment	2
CP - Consultation - other positive comment	1
CP - Consultation - question motivations/bias	3
CP - Consultation - question process	2
CP - Consultation - specific information	1
CP - Consultation - suspect foregone conclusion	1
CP - Follow-up - public communication/education	1
CP - Follow-up - wider debate	1
CP - Website - general	1
DS - Donor - availability issues/considerations	53
DS - Donor - responsibility for actions/know what they are getting into	10
DS - Donor function - providing medical solution/repair	8
DS - Donor motivation - gift/altruism	14
DS - Donor motivation - other	2
DS - Donor status - does have rights/responsibilities to child	2
DS - Donor status - is not parent/relation to child	29

Code	Count
DS - Donor status - is parent/relation to child	8
DS - Donor status - is part of child's make-up	2
DS - Donor status - is relation but not parent	1
DS - Donor status - is unclear/ambiguous	3
DS - Donor status - no rights/responsibilities to child	5
DS - Origin - makes no difference	1
IN - Age - 18 is too young	1
IN - Age - 18/when reaching adulthood	32
IN - Age - no minimum/from the start	5
IN - Age - no minimum/other factors	2
IN - Age - other comment	9
IN - Child - understand curiosity	13
IN - Child identity - should not be known by donor	3
IN - Child rights - may want to thank donor	17
IN - Child rights - no right to contact donor	7
IN - Child rights - no right/reason to access any information	13
IN - Child rights - not to feel obligated	2
IN - Child rights - other comment	18
IN - Child rights - should take priority	2
IN - Child rights - to information generally	28
IN - Child rights - to know origins/donor/parents	90
IN - Child rights - to understand process/implications	44
IN - Donor identity - depends on who the donor is	5
IN - Donor identity - family likely to know donor	1
IN - Donor identity - not relevant/necessary	44
IN - Donor identity - other comment	2
IN - Donor identity - should be available (general)	12
IN - Donor identity - should be optional/not mandatory	42
IN - Donor identity - should not be available (other/general)	17
IN - Donor identity - would not benefit child	3
IN - Donor identity/info - misrepresents contribution	16
IN - Donor rights - not to have relationship with child	3
IN - Donor rights - other comment	4
IN - Donor rights - to anonymity/lack of intrusion	36
IN - Donor rights - to know/contact family/child	4

Code	Count
IN - Donor status - different to adoption/surrogacy	4
IN - Donor status - different to blood/tissue/organ donor	2
IN - Donor status - different to donation (non specific)	1
IN - Donor status - different to egg/sperm donor	23
IN - Donor status - same as adoption/surrogacy	5
IN - Donor status - same as blood/tissue/organ donor	79
IN - Donor status - same as donation (non specific)	2
IN - Donor status - same as egg/sperm donor	42
IN - Logistics - database/infrastructure resourcing	1
IN - Logistics - donor screening	6
IN - Logistics - information storage/records	9
IN - Medical info - available for specific reasons/circumstances	82
IN - Medical info - not relevant/necessary	3
IN - Medical info - should be available (general)	45
IN - Option - between 1 and 2	2
IN - Option 1 - would be other choice	3
IN - Option 2 - for male children	1
IN - Option 2 - other comment	8
IN - Option 2 - preferred/if have to choose	3
IN - Option 2 - would be other choice	8
IN - Option 3 - for female children	1
IN - Option 3 - opposing comment	1
IN - Option 3 - other comment	8
IN - Option 3 - preferred/if have to choose	12
IN - Option 3 - would be other choice	7
IN - Option 5 - against/but if I have to choose	9
IN - Option 5 - would be other choice	3
IN - Overall - all/any information (option 3)	14
IN - Overall - balancing interests of parties	6
IN - Overall - depends on MST/PNT	17
IN - Overall - depends on other factor	2
IN - Overall - legal considerations	11
IN - Overall - minimum/only in some circumstances	2
IN - Overall - misuse of information	1
IN - Overall - more information than these options provide	4

Code	Count
IN - Overall - no information needed (option 1)	18
IN - Overall - not sure	5
IN - Overall - other comment	11
IN - Overall - rethink if/when research/knowledge progresses	9
IN - Overall - some/limited information (option 1)	1
IN - Overall - some/limited information (option 2)	4
IN - Overall decision - child's	13
IN - Overall decision - donor's	15
IN - Overall decision - flexible/mutual/depends	21
IN - Overall decision - parents'/family's	11
IN - Personal info - available for specific reasons/circumstances	12
IN - Personal info - not relevant/necessary	7
IN - Personal info - not sure	1
IN - Personal info - should be available (general)	25
IN - Personal info - should be optional/not mandatory	1
IN - Personal info - should not be available (other/general)	7
IN - Selected - no answer	6
IN - Selected - none selected	142
IN - Selected - option 1	111
IN - Selected - option 2	153
IN - Selected - option 3	153
IN - Selected - option 4	83
IN - Selected - option 5	514
O - Blank response/no comment	257
O - Other/general comment	2
O - Refer to other question	157
RF - Current legislation	1
RF - Current legislation - non UK	9
RF - External document	1
RF - HFEA	2
RF - Historical experience	7
RF - Other evidence/examples	2
RF - Participant - friend/relative/child with MD/similar disease	1
RF - Participant - info about	11
RF - Participant - other medical details	4

Code	Count
RF - Politics/government	1
RF - Relevant research	2
RF - Religion	17
RF - Specific individual/organisation/group	8
RF - Views of other people/participants	2
SC - DNA - nuclear DNA/genome not affected	15
SC - Mitochondria - function/form	9
SC - Mt DNA - does not determine identity/traits	60
SC - Mt DNA - maternal/female line	4
SC - Mt DNA - may affect identity/traits	2
SC - Mt DNA - other comment	4
SC - Mt DNA - small quantity/impact	39
SC - Mt DNA - suggested source for donation	1
SC - Other procedures - IVF/egg or sperm donation/surrogacy	3
SC - Other procedures - organ/tissue/blood donation	1
SC - Other procedures - stem cell donation	1
SC - Other procedures - vaccination	1
SC - Overall - assessing/managing risk	1
SC - Overall - balancing science/ethics/religion/society	1
SC - Overall - further research/trials/evidence	5
SC - Overall - new procedure/knowledge will grow	2
SC - Overall - other comment	2
SC - Overall - question about application	1
SC - Overall - understanding is limited	3
SC - Regulation - needed	1
SC - Regulation - other comment	1
SC - Regulation - specifics	1
SE - Ethical - consent/choice concern	1
SE - Ethical - consent/choice other	1
SE - General - current social/ethical expectations	3
SE - General - unforeseen problems/impacts/health issues	1
SE - Social - attitudes towards those treated	1
SE - Social - availability of counselling/testing/support	2
SE - Social - child emotional/psychological impact	13
SE - Social - child health/wellbeing improved	1

Code	Count
SE - Social - child health/wellbeing other	1
SE - Social - child ID/mixed genetic make-up	12
SE - Social - ID issues similar/no different to other procedures	1
SE - Social - impact on family relationships (not third parent)	1
SE - Social - impact on future generations	1
SE - Social - impact on lineage/traceability	2
SE - Social - legal implications/issues	1
SE - Social - no ID issues/implications foreseen	2
SE - Social - ongoing monitoring/follow-up	1
SE - Social - parent psychological impact	2
SE - Social - parent rights/responsibilities	10
SE - Social - third party parentage issues	4

5. Regulation of mitochondria replacement

If the law changed to allow mitochondria replacement to take place in a specialist clinic regulated by the HFEA, how should decisions be made on who can access this treatment? (Choose one response only)

- Clinics and their patients should decide when mitochondria replacement is appropriate in individual cases
- The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and, just for these diseases, permit clinics and patients to decide when it is appropriate in individual cases
- The regulator should decide which mitochondrial diseases are serious enough to require mitochondria replacement and also decide, just for these diseases, when it is appropriate in individual cases
- I do not think mitochondria replacement should be permitted in treatment at all

Please explain your choice.

Code	Count
AC - Acceptable - MST and PNT/general	5
AC - Not acceptable - MST and PNT/general	114
AC - Not acceptable - PNT	3
AC - Overall - unsure/no strong view	1
AG - Altering DNA - cloning/hybridisation	6
AG - Altering DNA - impact on germ line/lineage	10
AG - Altering DNA - not acceptable	3
AG - Costs/risks - outweigh benefits	7
AG - Disease - will not be eradicated/not a cure	2

Code	Count
AG - Donation - risk/exploitation	4
AG - Ethics - creation/destruction of egg/embryo	50
AG - Ethics - end does not justify means	3
AG - Ethics - general/too many ethical issues	13
AG - Ethics - interfering with evolution/playing god	27
AG - Ethics - judging value/worth of life (particularly PNT)	8
AG - Ethics - lack of consent/choice	1
AG - Ethics - no right to healthy/genetically related child	7
AG - Ethics - sanctity/dignity of human life	25
AG - Ethics - UK first in crossing ethical boundary	8
AG - Future - risks/impacts/unintended consequences	26
AG - Other - other comment	5
AG - Population - too big/would increase	1
AG - Preferable alternative - adoption	4
AG - Preferable alternative - decide not to conceive	4
AG - Preferable alternative - other treatment/cure of MD	20
AG - Preferable alternative - other/general	4
AG - Science - false hope/may not work	6
AG - Science - just because it is possible does not mean it should be done	6
AG - Science - role/motivation of scientists	4
AG - Science - understanding is limited	3
AG - Slippery slope - attitudes to euthanasia	1
AG - Slippery slope - cloning	6
AG - Slippery slope - concerns	27
AG - Slippery slope - designer babies/commoditisation	6
AG - Slippery slope - eugenics	10
AG - Social - general/too many social issues	1
AG - Social - impact on child/identity/psychology	13
AG - Social - impact on family relationships	4
AG - Social - legal implications/scenarios	3
AG - Social - prioritise other issues/solutions	2
AG - Social - third person as parent/donor	11
AG - Social - worth of MD sufferers/disabled people	4
AG - Wider issue - against artificial fertilisation	4
CO - Labelling of techniques - misleading/misunderstood	9

Code	Count
CP - Consultation - comment on question	19
CP - Consultation - outcomes	2
CP - Consultation - question motivations/bias	1
CP - Consultation - question process	6
DM - Clinicians - advise/recommend/input into decision	33
DM - Clinicians - are professional/should be trusted	3
DM - Clinicians - business interest/other motivation	28
DM - Clinicians - have closest knowledge	16
DM - Clinicians - other comment	7
DM - Clinicians - self-regulation/autonomy	6
DM - Clinicians - should decide	12
DM - Clinicians - should decide within boundaries set by regulator	25
DM - Criteria - base on science/facts	9
DM - Criteria - ensure safety	8
DM - Criteria - last resort only	3
DM - Criteria - medical/psychological considerations	4
DM - Criteria - none/any application should be allowed	8
DM - Criteria - none/treat all diseases/individuals	23
DM - Criteria - other	4
DM - Criteria - patient need/want/case by case	45
DM - Criteria - process/difficulty in setting criteria	15
DM - Criteria - seriousness of diseases/impacts	35
DM - Option 1 - could be introduced later	4
DM - Option 1 - opposing comment	4
DM - Option 1 - other comment	3
DM - Option 1 - would be other choice	2
DM - Option 2 - could be introduced later	2
DM - Option 2 - for MST only	1
DM - Option 2 - if shortage of donors	1
DM - Option 2 - opposing comment	3
DM - Option 2 - other comment	5
DM - Option 2 - preferred/if have to choose	11
DM - Option 3 - for MST only	1
DM - Option 3 - in specific/less clear cases	1
DM - Option 3 - opposing comment	9

Code	Count
DM - Option 3 - other comment	2
DM - Option 3 - preferred/if have to choose	18
DM - Option 4 - opposing comment	1
DM - Overall - alternative approach	3
DM - Overall - consider rare/new/uncategorised diseases	14
DM - Overall - different to other procedures	1
DM - Overall - lack of trust in government/regulator	5
DM - Overall - no/minimal risk of abuse/overuse	8
DM - Overall - not sure	1
DM - Overall - other comment	19
DM - Overall - rethink if needed/after set time	8
DM - Overall - risk of abuse/overuse	9
DM - Overall - similar/no different to other procedures	14
DM - Overall - this is workable/sensible option	9
DM - Parliament - should have ultimate control	32
DM - Patient/clinician - able to influence decision	1
DM - Patient/clinician - have closest knowledge	10
DM - Patient/clinician - joint decision	49
DM - Patient/clinician - joint decision within boundaries set by regulator	47
DM - Patient/clinician - self-regulation	3
DM - Patients - have closest knowledge	10
DM - Patients - involvement in decision/choice	20
DM - Patients - may go elsewhere/abroad	2
DM - Patients - other comment	2
DM - Patients - question motivation	7
DM - Patients - should decide	32
DM - Patients - should decide within boundaries set by regulator	8
DM - Regulator - adds bureaucracy/cost/distress	25
DM - Regulator - appeals process	4
DM - Regulator - closer involvement upfront/early on	19
DM - Regulator - doesn't make it OK/ethical	40
DM - Regulator - helps ensure clinic performance/quality	19
DM - Regulator - helps ensure safety/quality	5
DM - Regulator - helps limit cost/distribute limited resource	8
DM - Regulator - helps prevent abuse/overuse/ensure legality	35

Code	Count
DM - Regulator - helps public acceptability	7
DM - Regulator - impartial/independent/trusted	8
DM - Regulator - international implications	5
DM - Regulator - involvement is necessary (general/other)	30
DM - Regulator - makes decisions on individual cases (option 3)	13
DM - Regulator - must be accountable/trustworthy	4
DM - Regulator - not appropriate to involve	20
DM - Regulator - not necessary to involve	8
DM - Regulator - other comment	20
DM - Regulator - oversight/review role	26
DM - Regulator - politically/financially driven	9
DM - Regulator - reference existing PGD approach	12
DM - Regulator - sets boundaries not individual cases (option 2)	66
DM - Regulator - should not be overburdened	5
DM - Regulator - strict/stringent rules needed	20
DM - Regulator - too distant/generalist/lacking in knowledge	27
DM - Regulator - will not be effective	36
DM - Resourcing - concern over NHS resource	2
DM - Resourcing - other comment	5
DM - Resourcing - should be from patients/privately	4
DM - Resourcing - should not take precedence	2
DM - Selected - no answer	12
DM - Selected - none selected	12
DM - Selected - option 1	232
DM - Selected - option 2	185
DM - Selected - option 3	55
DM - Selected - option 4	547
DM - Timescales - should be fast/efficient	4
O - Blank response/no comment	204
O - Refer to other question	178
RF - Current legislation	8
RF - Current legislation - non UK	11
RF - HFEA	37
RF - Historical experience	29
RF - Media coverage	1

Code	Count
RF - Participant - friend/relative/child with MD/similar disease	4
RF - Participant - has MD/similar disease	1
RF - Participant - info about	6
RF - Participant - other medical details	2
RF - Politics/government	19
RF - Relevant research	2
RF - Religion	9
RF - Views of other people/participants	4
SC - Germ line - could reduce in diversity	1
SC - MD - testing mothers	2
SC - MD - variety of forms/impacts	22
SC - Mitochondria - function/form	3
SC - Mt DNA - does not determine identity/traits	1
SC - Other procedures - abortion/termination	9
SC - Other procedures - adoption	1
SC - Other procedures - genetic techniques/gene therapy	6
SC - Other procedures - IVF/egg or sperm donation/surrogacy	3
SC - Other procedures - organ/tissue/blood donation	6
SC - Other procedures - other/general	4
SC - Overall - nature of medicine/science	4
SC - Overall - new procedure/knowledge will grow	7
SC - Overall - other comment	3
SC - Overall - question about application	2
SC - Overall - understanding is limited	3
SC - Progress - has gone too far to stop now	2
SC - Progress - reducing MD is good/positive	3
SC - Safety - other comment	3
SE - Ethical - benefits small number	3
SE - Ethical - embryo rights/usage other	3
SE - Ethical - equity of provision	16
SE - Ethical - ethical imperative to intervene	4
SE - Ethical - having healthy children is a right	2
SE - Ethical - having healthy children not a right/essential	1
SE - Ethical - implications	1
SE - Ethical - no slippery slope/not crossing boundary	2

Code	Count
SE - Ethical - slippery slope generally/crossing boundary	5
SE - Ethical - slippery slope to designer babies/commoditisation	6
SE - Ethical tradeoffs - evolution vs familial distress	1
SE - Ethical tradeoffs - safety vs progress	1
SE - Ethical tradeoffs - society vs individual	1
SE - General - benefits outweigh issues	1
SE - General - current social/ethical expectations	4
SE - General - no implications/concerns (No)	1
SE - General - unforeseen problems/impacts/health issues	4
SE - Social - benefits to potential parents/families/relationships	4
SE - Social - child awareness/understanding	1
SE - Social - child health/wellbeing improved	5
SE - Social - child health/wellbeing other	6
SE - Social - child rights	5
SE - Social - donor considerations	2
SE - Social - impact on future generations	1
SE - Social - issues from having MD/disability	3
SE - Social - legal implications/issues	1
SE - Social - ongoing monitoring/follow-up	2
SE - Social - overpopulation	1
SE - Social - parent rights/responsibilities	1
SE - Social - parents should not be pressurised	1

6. Should the law be changed?

In Question 1, we asked for your views on the mitochondria replacement techniques MST and PNT. Please could you now tell us if you think the law should be changed to allow (one or both of) these techniques to be made available to people who are at risk of passing on mitochondrial disease to their child?

Code	Count
AC - Acceptable - MST and PNT/general	5
AC - Not acceptable - MST and PNT/general	114
AC - Not acceptable - PNT	3
AC - Overall - unsure/no strong view	1
AG - Altering DNA - cloning/hybridisation	6
AG - Altering DNA - impact on germ line/lineage	10
AG - Altering DNA - not acceptable	3

Code	Count
AG - Costs/risks - outweigh benefits	7
AG - Disease - will not be eradicated/not a cure	2
AG - Donation - risk/exploitation	4
AG - Ethics - creation/destruction of egg/embryo	50
AG - Ethics - end does not justify means	3
AG - Ethics - general/too many ethical issues	13
AG - Ethics - interfering with evolution/playing god	27
AG - Ethics - judging value/worth of life (particularly PNT)	8
AG - Ethics - lack of consent/choice	1
AG - Ethics - no right to healthy/genetically related child	7
AG - Ethics - sanctity/dignity of human life	25
AG - Ethics - UK first in crossing ethical boundary	8
AG - Future - risks/impacts/unintended consequences	26
AG - Other - other comment	5
AG - Population - too big/would increase	1
AG - Preferable alternative - adoption	4
AG - Preferable alternative - decide not to conceive	4
AG - Preferable alternative - other treatment/cure of MD	20
AG - Preferable alternative - other/general	4
AG - Science - false hope/may not work	6
AG - Science - just because it is possible does not mean it should be done	6
AG - Science - role/motivation of scientists	4
AG - Science - understanding is limited	3
AG - Slippery slope - attitudes to euthanasia	1
AG - Slippery slope - cloning	6
AG - Slippery slope - concerns	27
AG - Slippery slope - designer babies/commoditisation	6
AG - Slippery slope - eugenics	10
AG - Social - general/too many social issues	1
AG - Social - impact on child/identity/psychology	13
AG - Social - impact on family relationships	4
AG - Social - legal implications/scenarios	3
AG - Social - prioritise other issues/solutions	2
AG - Social - third person as parent/donor	11
AG - Social - worth of MD sufferers/disabled people	4

Code	Count
AG - Wider issue - against artificial fertilisation	4
CO - Labelling of techniques - misleading/misunderstood	9
CP - Consultation - comment on question	19
CP - Consultation - outcomes	2
CP - Consultation - question motivations/bias	1
CP - Consultation - question process	6
DM - Clinicians - advise/recommend/input into decision	33
DM - Clinicians - are professional/should be trusted	3
DM - Clinicians - business interest/other motivation	28
DM - Clinicians - have closest knowledge	16
DM - Clinicians - other comment	7
DM - Clinicians - self-regulation/autonomy	6
DM - Clinicians - should decide	12
DM - Clinicians - should decide within boundaries set by regulator	25
DM - Criteria - base on science/facts	9
DM - Criteria - ensure safety	8
DM - Criteria - last resort only	3
DM - Criteria - medical/psychological considerations	4
DM - Criteria - none/any application should be allowed	8
DM - Criteria - none/treat all diseases/individuals	23
DM - Criteria - other	4
DM - Criteria - patient need/want/case by case	45
DM - Criteria - process/difficulty in setting criteria	15
DM - Criteria - seriousness of diseases/impacts	35
DM - Option 1 - could be introduced later	4
DM - Option 1 - opposing comment	4
DM - Option 1 - other comment	3
DM - Option 1 - would be other choice	2
DM - Option 2 - could be introduced later	2
DM - Option 2 - for MST only	1
DM - Option 2 - if shortage of donors	1
DM - Option 2 - opposing comment	3
DM - Option 2 - other comment	5
DM - Option 2 - preferred/if have to choose	11
DM - Option 3 - for MST only	1

Code	Count
DM - Option 3 - in specific/less clear cases	1
DM - Option 3 - opposing comment	9
DM - Option 3 - other comment	2
DM - Option 3 - preferred/if have to choose	18
DM - Option 4 - opposing comment	1
DM - Overall - alternative approach	3
DM - Overall - consider rare/new/uncategorised diseases	14
DM - Overall - different to other procedures	1
DM - Overall - lack of trust in government/regulator	5
DM - Overall - no/minimal risk of abuse/overuse	8
DM - Overall - not sure	1
DM - Overall - other comment	19
DM - Overall - rethink if needed/after set time	8
DM - Overall - risk of abuse/overuse	9
DM - Overall - similar/no different to other procedures	14
DM - Overall - this is workable/sensible option	9
DM - Parliament - should have ultimate control	32
DM - Patient/clinician - able to influence decision	1
DM - Patient/clinician - have closest knowledge	10
DM - Patient/clinician - joint decision	49
DM - Patient/clinician - joint decision within boundaries set by regulator	47
DM - Patient/clinician - self-regulation	3
DM - Patients - have closest knowledge	10
DM - Patients - involvement in decision/choice	20
DM - Patients - may go elsewhere/abroad	2
DM - Patients - other comment	2
DM - Patients - question motivation	7
DM - Patients - should decide	32
DM - Patients - should decide within boundaries set by regulator	8
DM - Regulator - adds bureaucracy/cost/distress	25
DM - Regulator - appeals process	4
DM - Regulator - closer involvement upfront/early on	19
DM - Regulator - doesn't make it OK/ethical	40
DM - Regulator - helps ensure clinic performance/quality	19
DM - Regulator - helps ensure safety/quality	5

Code	Count
DM - Regulator - helps limit cost/distribute limited resource	8
DM - Regulator - helps prevent abuse/overuse/ensure legality	35
DM - Regulator - helps public acceptability	7
DM - Regulator - impartial/independent/trusted	8
DM - Regulator - international implications	5
DM - Regulator - involvement is necessary (general/other)	30
DM - Regulator - makes decisions on individual cases (option 3)	13
DM - Regulator - must be accountable/trustworthy	4
DM - Regulator - not appropriate to involve	20
DM - Regulator - not necessary to involve	8
DM - Regulator - other comment	20
DM - Regulator - oversight/review role	26
DM - Regulator - politically/financially driven	9
DM - Regulator - reference existing PGD approach	12
DM - Regulator - sets boundaries not individual cases (option 2)	66
DM - Regulator - should not be overburdened	5
DM - Regulator - strict/stringent rules needed	20
DM - Regulator - too distant/generalist/lacking in knowledge	27
DM - Regulator - will not be effective	36
DM - Resourcing - concern over NHS resource	2
DM - Resourcing - other comment	5
DM - Resourcing - should be from patients/privately	4
DM - Resourcing - should not take precedence	2
DM - Selected - no answer	12
DM - Selected - none selected	12
DM - Selected - option 1	232
DM - Selected - option 2	185
DM - Selected - option 3	55
DM - Selected - option 4	547
DM - Timescales - should be fast/efficient	4
Holding	1
O - Blank response/no comment	204
O - Refer to other question	178
RF - Current legislation	8
RF - Current legislation - non UK	11

Code	Count
RF - HFEA	37
RF - Historical experience	29
RF - Media coverage	1
RF - Participant - friend/relative/child with MD/similar disease	4
RF - Participant - has MD/similar disease	1
RF - Participant - info about	6
RF - Participant - other medical details	2
RF - Politics/government	19
RF - Relevant research	2
RF - Religion	9
RF - Views of other people/participants	4
SC - Germ line - could reduce in diversity	1
SC - MD - testing mothers	2
SC - MD - variety of forms/impacts	22
SC - Mitochondria - function/form	3
SC - Mt DNA - does not determine identity/traits	1
SC - Other procedures - abortion/termination	9
SC - Other procedures - adoption	1
SC - Other procedures - genetic techniques/gene therapy	6
SC - Other procedures - IVF/egg or sperm donation/surrogacy	3
SC - Other procedures - organ/tissue/blood donation	6
SC - Other procedures - other/general	4
SC - Overall - nature of medicine/science	4
SC - Overall - new procedure/knowledge will grow	7
SC - Overall - other comment	3
SC - Overall - question about application	2
SC - Overall - understanding is limited	3
SC - Progress - has gone too far to stop now	2
SC - Progress - reducing MD is good/positive	3
SC - Safety - other comment	3
SE - Ethical - benefits small number	3
SE - Ethical - embryo rights/usage other	3
SE - Ethical - equity of provision	16
SE - Ethical - ethical imperative to intervene	4
SE - Ethical - having healthy children is a right	2

Code	Count
SE - Ethical - having healthy children not a right/essential	1
SE - Ethical - implications	1
SE - Ethical - no slippery slope/not crossing boundary	2
SE - Ethical - slippery slope generally/crossing boundary	5
SE - Ethical - slippery slope to designer babies/commoditisation	6
SE - Ethical tradeoffs - evolution vs familial distress	1
SE - Ethical tradeoffs - safety vs progress	1
SE - Ethical tradeoffs - society vs individual	1
SE - General - benefits outweigh issues	1
SE - General - current social/ethical expectations	4
SE - General - no implications/concerns (No)	1
SE - General - unforeseen problems/impacts/health issues	4
SE - Social - benefits to potential parents/families/relationships	4
SE - Social - child awareness/understanding	1
SE - Social - child health/wellbeing improved	5
SE - Social - child health/wellbeing other	6
SE - Social - child rights	5
SE - Social - donor considerations	2
SE - Social - impact on future generations	1
SE - Social - issues from having MD/disability	3
SE - Social - legal implications/issues	1
SE - Social - ongoing monitoring/follow-up	2
SE - Social - overpopulation	1
SE - Social - parent rights/responsibilities	1
SE - Social - parents should not be pressurised	1

7. Further considerations

Are there any other considerations you think decision makers should take into account when deciding whether or not to permit mitochondria replacement?

Code	Count
AC - Acceptable - MST	2
AC - Acceptable - MST and PNT/general	6
AC - Acceptable with caveat - MST and PNT/general	4
AC - Not acceptable - MST and PNT/general	21
AC - Not acceptable - PNT	2

Code	Count
AC - Overall - understand issue/have sympathy	11
AC - Preference - MST over PNT	1
AG - Altering DNA - cloning/hybridisation	35
AG - Altering DNA - impact on germ line/lineage	36
AG - Altering DNA - not acceptable	28
AG - Cost - too much/cannot be justified	5
AG - Costs/risks - outweigh benefits	2
AG - Disease - will not be eradicated/not a cure	8
AG - Donation - risk/exploitation	9
AG - Ethics - creation/destruction of egg/embryo	10
AG - Ethics - embryo (mainly PNT) creation/destruction	100
AG - Ethics - end does not justify means	34
AG - Ethics - general/too many ethical issues	23
AG - Ethics - interfering with evolution/playing god	66
AG - Ethics - lack of consent/choice	1
AG - Ethics - no right to healthy/genetically related child	38
AG - Ethics - sanctity/dignity of human life	43
AG - Ethics - UK first in crossing ethical boundary	15
AG - Future - risks/impacts/unintended consequences	59
AG - Overall - not our decision to make/no right	6
AG - Population - too big/would increase	4
AG - Preferable alternative - adoption	16
AG - Preferable alternative - counselling/support	2
AG - Preferable alternative - decide not to conceive	2
AG - Preferable alternative - donor eggs	26
AG - Preferable alternative - donor embryo	2
AG - Preferable alternative - IVF	2
AG - Preferable alternative - other treatment/cure of MD	75
AG - Preferable alternative - other/general	16
AG - Preferable alternative - screening eggs/embryos	1
AG - Regulation - can't guarantee limits	5
AG - Regulation - may not be consistent across the board	3
AG - Science - false hope/may not work	70
AG - Science - just because it is possible does not mean it should be done	11
AG - Science - other comment	2

Code	Count
AG - Science - role/motivation of scientists	37
AG - Science - understanding is limited	3
AG - Slippery slope - attitudes to euthanasia	1
AG - Slippery slope - cloning	20
AG - Slippery slope - concerns	38
AG - Slippery slope - designer babies/commoditisation	18
AG - Slippery slope - eugenics	15
AG - Social - general/too many social issues	4
AG - Social - impact on child/identity/psychology	58
AG - Social - impact on donor/donor considerations	7
AG - Social - impact on family relationships	4
AG - Social - impact on parents	5
AG - Social - legal implications/scenarios	1
AG - Social - prioritise other issues/solutions	8
AG - Social - third person as parent/donor	52
AG - Social - will never be able to tackle all diseases	1
AG - Wider issue - against artificial fertilisation	3
CO - Alternatives - other comment	2
CO - Availability - NHS cover	3
CO - Availability - NHS should not cover/fund privately	1
CO - Business interest/involvement	4
CO - Cost/funding - general/who pays	18
CO - Criteria - cost/value	4
CO - Criteria - family situation/ability to provide	2
CO - Criteria - identifying those in need	4
CO - Criteria - medical evidence/advice	3
CO - Criteria - other	6
CO - Criteria - parent/patient choice	10
CO - Criteria - patient need/appropriateness	1
CO - Criteria - patient/clinician joint decision	7
CO - Criteria - regulator should decide	1
CO - Criteria - safety	21
CO - Criteria - seriousness of diseases/impacts	6
CO - Criteria - success rate/efficacy/efficiency	12
CO - Criteria - where proven risk to offspring	3

Code	Count
CO - Donation - availability/origin	4
CO - Donation - risk/exploitation	1
CO - Embryo or egg rights/life - concern	1
CO - Embryo or egg rights/life - general/other	3
CO - Ethics - different to designer embryos/cloning	6
CO - Ethics - interfering with evolution/playing god	3
CO - Ethics - other comment	7
CO - Ethics - should prevail	6
CO - Identity - concerns	1
CO - Labelling of techniques - misleading/misunderstood	7
CO - MST - could be more publically/ethically acceptable	4
CO - MST & PNT - other comparative comment	1
CO - Other priorities - concept of family	1
CO - Other priorities - MD diagnosis	1
CO - Other priorities - other heath issues	2
CO - Other priorities - other MD treatment/cure	1
CO - Other priorities - poverty	1
CO - Other priorities - psychological/psychiatric care	1
CO - Overall - complex/unique decision/new territory	9
CO - Overall - needs 'humanising'	1
CO - Overall - needs rational/objective consideration	5
CO - Overall - no further considerations	29
CO - Overall - other comment	3
CO - Overall - same as other IVF/fertility treatment	6
CO - Overall - similar to other existing treatments/techniques	5
CO - Overall - speed of introduction	4
CO - Overall - weigh risks vs benefits/net gain	3
CO - Patients - follow up studies/monitoring	21
CO - Patients - information provision/involvement	16
CO - Patients - may go elsewhere/abroad	2
CO - Patients - support/counselling	9
CO - Population - growth/general	2
CO - Regulation - international considerations	6
CO - Regulation - limitation of use	10
CO - Regulation - needed	6

Code	Count
CO - Regulation - not needed	1
CO - Regulation - other comment	1
CO - Regulation - specifics	22
CO - Regulation - would prevent slippery slope	1
CO - Safety - risks is always present with medical procedures	2
CO - Safety - risks vs benefits	2
CO - Science - further research/trials/evidence	18
CO - Science - other comment	2
CO - Science - should prevail	9
CO - Slippery slope - designer babies/commoditisation	7
CO - Slippery slope - general	10
CO - Social - number of cases	11
CO - Social - parents should not be pressurised	3
CP - Consultation - comment on question	2
CP - Consultation - comment on response form	3
CP - Consultation - cost concern	1
CP - Consultation - lack of information	1
CP - Consultation - other negative comment	2
CP - Consultation - other positive comment	3
CP - Consultation - outcomes	1
CP - Consultation - poor publicity/lack of response	4
CP - Consultation - question motivations/bias	8
CP - Consultation - timing	3
CP - Consultation - welcomed	12
CP - Follow-up - further info on specific topic/s	3
CP - Follow-up - offer of help/further info	3
CP - Follow-up - other	2
CP - Follow-up - public communication/education	16
CP - Follow-up - role of specific sector/group	4
CP - Follow-up - wider debate	5
CP - Respondents - bear in mind experience/knowledge	3
CP - Respondents - comment on response rate	1
CP - Specific groups/views - disregard/do not give undue weight	23
CP - Specific groups/views - other comment	4
CP - Specific groups/views - talk to/consider	35

Code	Count
CP - Website - difficulty	1
CP - Website - lack of information	1
CP - Website - positive comment	1
CP - Website - video	1
CP - Wider issues - fertility treatment overall	2
CP - Wider issues - genetic disease	1
CP - Wider issues - pre-implantation techniques	1
CP - Wider issues - use of animals in research	1
DM - Clinicians - other comment	1
DM - Overall - consider rare/new/uncategorised diseases	1
DM - Overall - other comment	10
DM - Regulator - doesn't make it OK/ethical	1
DM - Regulator - sets boundaries not individual cases (option 2)	1
DS - Donor - payment	3
DS - Donor - responsibility for actions/know what they are getting into	1
DS - Donor function - providing medical solution/repair	2
DS - Donor status - no rights/responsibilities to child	1
DS - Mitochondria - complex/uncomfortable donation	1
DS - Mitochondria - similar to blood	1
DS - Mitochondria - similar to bone marrow	2
DS - Mitochondria - similar to organ	1
DS - Origin - allow choice	1
DS - Origin - should be family member/close relative	1
DS - Parents - payment	1
DS - Parents - responsibility for actions/know what they are getting into	2
FA - Benefits - outweigh cost/other considerations	7
FA - Disease - avoidance important/positive	9
FA - Disease - eradicate	9
FA - Disease - impact on families/sufferers	49
FA - Disease - scale of suffering underestimated	2
FA - Ethics - ethical imperative to intervene	17
FA - Ethics - no concerns	3
FA - Ethics - right to healthy/genetically related child	6
FA - MST - does not destroy embryos	2
FA - Overall - better than other techniques	5

Code	Count
FA - Overall - no reason not to allow	4
FA - Safety - changing law allow techniques to developed safely/responsibly	1
FA - Safety - these techniques are safe/risks acceptable	8
FA - Science - allow to progress as far as it can	2
FA - Science - could lead to new treatments (MD or other diseases)	6
FA - Science - important/positive	9
FA - Science - natural progress	2
FA - Science - other comment	3
FA - Science - UK as a leader in new techniques	5
FA - Slippery slope - not a concern	6
FA - Social - benefits to potential parents/families	24
FA - Social - health/wellbeing of the child	34
FA - Social - reduces burden on services/NHS	17
HOLDING	1
IN - Age - 18/when reaching adulthood	1
IN - Donor identity - should be available (general)	1
IN - Donor rights - other comment	2
IN - Logistics - donor screening	6
IN - Logistics - information storage/records	4
IN - Medical info - available for specific reasons/circumstances	1
IN - Medical info - should be available (general)	1
IN - Overall - conflicts of rights/interests	1
IN - Personal info - should be available (general)	1
LS - Comparison - like IVF/egg/sperm donation	1
LS - Conditions - allow testing/trials only at first	1
LS - Law should change - MD only	3
LS - Law should change - MST&PNT/general	23
LS - Law should change - quickly/asap	7
LS - Law should change w caveats - MST	1
LS - Law should change w caveats - MST&PNT/general	5
LS - Law should NOT change - MST&PNT/general	24
LS - Other - international impetus/influence/implications	7
LS - Other - other comment on law/legal system	5
LS - Other - punishment for undertaking techniques	10
LS - Other - re-examine if needed/after set period	1

Code	Count
LS - Other - specific related laws/legislation	7
LS - Other - specific suggestions for detail	3
O - Blank response/no comment	68
O - Not sure/do not know	4
O - Other/general comment	3
O - Refer to other question	21
O - Refer to other response	2
RF - Current legislation	5
RF - Current legislation - non UK	33
RF - External document	9
RF - External website	4
RF - HFEA	12
RF - Historical experience	69
RF - Media coverage	16
RF - NICE	1
RF - Other evidence/examples	7
RF - Participant - friend/relative/child with MD/similar disease	19
RF - Participant - has MD/similar disease	10
RF - Participant - info about	22
RF - Participant - other medical details	6
RF - Participant - personal details	2
RF - Politics/government	26
RF - Relevant research	12
RF - Religion	45
RF - Specific individual/organisation/group	23
RF - Views of other people/participants	46
SC - DNA - natural mixing	1
SC - DNA - nuclear DNA/genome not affected	2
SC - DNA - other comment	3
SC - Germ line - other comment	1
SC - MD - variety of forms/impacts	7
SC - Mitochondria - function/form	3
SC - Mt DNA - does not determine identity/traits	3
SC - Mt DNA - limited amount/types	1
SC - Mt DNA - origin/not human	1

Code	Count
SC - Mt DNA - other comment	8
SC - Mt DNA - small quantity/impact	2
SC - Mt DNA - suggested source for donation	2
SC - Other procedures - abortion/termination	2
SC - Other procedures - donor cytoplasm	1
SC - Other procedures - IVF/egg or sperm donation/surrogacy	6
SC - Other procedures - organ/tissue/blood donation	4
SC - Other procedures - other/general	1
SC - Overall - balancing science/ethics/religion/society	1
SC - Overall - further research/trials/evidence	1
SC - Overall - invest in other priorities/solutions	2
SC - Overall - motivation of scientists	2
SC - Overall - other comment	7
SC - Overall - question about application	3
SC - Overall - specific consideration for PNT	1
SC - Overall - trust/mistrust of scientists	2
SC - Progress - natural consequence/function of humanity	1
SC - Progress - other comment	2
SC - Progress - requires caution	3
SC - Safety - other comment	1
SE - Ethical - benefits small number	2
SE - Ethical - consent/choice concern	3
SE - Ethical - consent/choice other	1
SE - Ethical - end justifies means	1
SE - Ethical - equity of provision	8
SE - Ethical - interfering/playing god already happens	1
SE - Ethical - judging value/worth of life	1
SE - Ethical - no right to healthy/genetically related child	2
SE - Ethical - slippery slope generally/crossing boundary	1
SE - Ethical - society vs individual	4
SE - General - current social/ethical expectations	2
SE - General - implications	1
SE - General - implications cannot be understood	1
SE - General - unforeseen problems/impacts/health issues	6
SE - Social - attitudes towards disabled people/MD sufferers	10

Code	Count
SE - Social - attitudes towards those not treated	3
SE - Social - attitudes towards those treated	2
SE - Social - availability of counselling/testing/support	1
SE - Social - benefit to future generations	2
SE - Social - child awareness/understanding	3
SE - Social - child emotional/psychological impact	4
SE - Social - child health/wellbeing other	4
SE - Social - child ID/mixed genetic make-up	2
SE - Social - child impacts/damage (other/general)	1
SE - Social - child rights	5
SE - Social - donor considerations	1
SE - Social - ID issues less than other procedures	1
SE - Social - ID/issues complex/different for everyone	1
SE - Social - impact on family relationships (not third parent)	3
SE - Social - impact on future generations	11
SE - Social - issues from having MD/disability	1
SE - Social - legal implications/issues	2
SE - Social - no ID issues/implications foreseen	2
SE - Social - no third party parentage issues	5
SE - Social - overall societal benefit/not harmful	2
SE - Social - overall societal impact	12
SE - Social - parent rights/responsibilities	4
SE - Social - public/societal response/fear	2
SE - Social - risk losing valuable individuals	3
SE - Social - third party parentage issues	3
SE - Social - who should know the details	1

8. Non-questionnaire responses

Code	Count
AC - Acceptable - MST and PNT/general	38
AC - Acceptable with caveat - MST and PNT/general	1
AC - Not acceptable - MST	1
AC - Not acceptable - MST and PNT/general	297
AC - Not acceptable - PNT	1
AC - Overall - understand issue/have sympathy	20

Code	Count
AG - Altering DNA - cloning/hybridisation	17
AG - Altering DNA - impact on germ line/lineage	100
AG - Altering DNA - not acceptable	24
AG - Cost - too much/cannot be justified	3
AG - Costs/risks - outweigh benefits	20
AG - Donation - risk/exploitation	5
AG - Ethics - embryo (mainly PNT) creation/destruction	229
AG - Ethics - end does not justify means	13
AG - Ethics - general/too many ethical issues	29
AG - Ethics - interfering with evolution/playing god	91
AG - Ethics - lack of consent/choice	13
AG - Ethics - no right to healthy/genetically related child	3
AG - Ethics - other comment	7
AG - Ethics - sanctity/dignity of human life	181
AG - Ethics - UK first in crossing ethical boundary	109
AG - Future - risks/impacts/unintended consequences	173
AG - MST & PNT - both involve IVF/embryo destruction	4
AG - Population - too big/would increase	2
AG - Preferable alternative - adoption	6
AG - Preferable alternative - counselling/support	1
AG - Preferable alternative - IVF	1
AG - Preferable alternative - other treatment/cure of MD	118
AG - Preferable alternative - other/general	103
AG - Preferable alternative - screening eggs/embryos	2
AG - Regulation - can't guarantee limits	2
AG - Science - false hope/may not work	3
AG - Science - just because it is possible does not mean it should be done	11
AG - Science - other comment	5
AG - Science - role/motivation of scientists	31
AG - Science - understanding is limited	18
AG - Slippery slope - cloning	92
AG - Slippery slope - concerns	17
AG - Slippery slope - designer babies/commoditisation	99
AG - Slippery slope - eugenics	28
AG - Slippery slope - normalising GM	10

Code	Count
AG - Social - hardship is natural/contributes to strength of society	5
AG - Social - impact on child/identity/psychology	198
AG - Social - impact on donor/donor considerations	4
AG - Social - impact on family relationships	33
AG - Social - impact on parents	8
AG - Social - legal implications/scenarios	3
AG - Social - other comment	7
AG - Social - prioritise other issues/solutions	2
AG - Social - third person as parent/donor	249
AG - Social - worth of MD sufferers/disabled people	7
AG - Wider issue - against artificial fertilisation	1
CO - Embryo or egg rights/life - concern	2
CO - Embryo or egg rights/life - not a concern	1
CO - Ethics - different to designer embryos/cloning	3
CO - Ethics - other comment	3
CO - Identity - child should know about conception	1
CO - Identity - concerns	1
CO - Patients - information provision/involvement	2
CO - Regulation - international considerations	1
CO - Safety - risks vs benefits	4
CO - Science - further research/trials/evidence	6
CO - Science - mitochondrial function	4
CO - Science - other comment	4
CO - Science - participant understanding	7
CO - Slippery slope - designer babies/commoditisation	1
CO - Social - number of cases	4
CO - Social - parents should not be pressurised	2
CO - Social - risk losing valuable individuals	1
CP - Consultation - comment on question	2
CP - Consultation - other comment	11
CP - Consultation - other negative comment	6
CP - Consultation - other positive comment	5
CP - Consultation - poor publicity/lack of response	3
CP - Consultation - timing	4
CP - Consultation - welcomed	4

Code	Count
CP - Specific groups/views - disregard/do not give undue weight	2
CP - Specific groups/views - talk to/consider	1
CP - Website - difficulty	6
CP - Website - general	2
DM - Regulator - helps public acceptability	1
DM - Regulator - involvement is necessary (general/other)	3
DS - Donor status - is parent/relation to child	2
DS - Donor status - is unclear/ambiguous	1
DS - Donor status - legal considerations	1
DS - Mitochondria - different to blood	1
DS - Mitochondria - similar to egg/sperm/embryo/IVF	2
DS - Parents - responsibility for actions/know what they are getting into	1
FA - Benefits - outweigh cost/other considerations	2
FA - Disease - avoidance important/positive	6
FA - Disease - eradicate	6
FA - Disease - impact on families/sufferers	18
FA - Disease - scale of suffering underestimated	1
FA - Ethics - ethical imperative to intervene	2
FA - Ethics - right to healthy/genetically related child	2
FA - Identity - no concerns	1
FA - MST and PNT - better/alternative to current options	1
FA - Science - important/positive	4
FA - Science - nuclear DNA not altered	1
FA - Social - benefits to potential parents/families	7
FA - Social - general benefit to society/public health	1
FA - Social - health/wellbeing of the child	8
LS - Comparison - like IVF/egg/sperm donation	1
LS - Comparison - like organ/blood/tissue	1
LS - Further exploration needed - general/both	3
LS - International - impetus/influence/implications	1
LS - Law should change - MST&PNT/general	5
LS - Law should NOT change - MST&PNT/general	222
LS - Other - international impetus/influence/implications	12
LS - Other - lack of trust in government/regulators	2
LS - Other - punishment for undertaking techniques	56

Code	Count
LS - Other - specific related laws/legislation	2
LS - Punishment for undertaking techniques	1
O - Additional attachment	1
O - Other/general comment	43
O - Refer to other response	1
RF - Culture/literature	3
RF - Current legislation	7
RF - Current legislation - non UK	145
RF - External event/discussion	4
RF - HFEA	7
RF - Historical experience	19
RF - Participant - friend/relative/child with MD/similar disease	36
RF - Participant - has MD/similar disease	7
RF - Participant - info about	60
RF - Participant - personal details	11
RF - Politics/government	10
RF - Relevant research	37
RF - Religion	105
RF - Scientific review panel	1
RF - Specific individual/organisation/group	18
RF - Views of other people/participants	9
SC - DNA - nuclear DNA/genome not affected	1
SC - DNA - other comment	2
SC - MD - diagnosis	2
SC - Mt DNA - does not determine identity/traits	1
SC - Mt DNA - may affect identity/traits	1
SC - Mt DNA - other comment	1
SC - Other procedures - adoption	1
SC - Other procedures - IVF/egg or sperm donation/surrogacy	1
SC - Other procedures - organ/tissue/blood donation	2
SC - Overall - other comment	3
SC - Overall - trust/mistrust of scientists	1
SC - Progress - other comment	2
SC - Progress - reducing MD is good/positive	1
SC - Safety - other comment	3

Code	Count
SE - Ethical - consent/choice other	1
SE - Ethical - embryo rights/usage other	1
SE - Ethical - slippery slope generally/crossing boundary	1
SE - Ethical - slippery slope/similar to cloning	2
SE - Ethical - UK first in crossing ethical boundary	2
SE - General - implications	2
SE - General - other procedures acceptable/better	1
SE - Social - child rights	1
SE - Social - cost/resources	1
SE - Social - donor/child relationship difficulties	1
SE - Social - issues from having MD/disability	2
SE - Social - public/societal response/fear	1
SE - Social - third party parentage issues	1